

A Study of Assembly Bill A-999



A Report to the New Jersey State Assembly by the

Mandated Health Benefits Advisory Commission



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Appendix A Report to the New Jersey Mandated Health Benefits Advisory Commission, February 2007, by Donna Novak, CFA, ASA, MAAA, MBA, NovaRest Consulting

Introduction

On November 6, 2006 the Mandated Health Benefits Advisory Commission (Commission) was asked to issue a report on Assembly Bill 999 (A-999). The Commission undertook the study with the understanding that it is charged by law with investigating the many facets of the impact of A-999. With this in mind and considering the limited time and resources of the Commission and Department staff, an actuarial firm with experience in such investigations, NovaRest, was engaged to study this bill and provide an estimate of the impact of A-999 on health insurance premiums. The Commission understands that the Legislature desires that the greater emphasis of these studies be on the financial impact on the insurance market, including the impact on price and on the availability of necessary medical services.

It is important to note that although the Commission invited public comment, no comments were received.

Summary

The consultant's report indicates that this bill, if enacted, would result in average family premium increases of approximately .8 %

The assumptions underlying the consultant's report include 1) the prevalence of autism in the insured population is the same as that reported for the general population, and 2) all medically necessary mandated therapy for covered people will be paid by insurance (rather than educational or other government programs.) and 3) Carriers would be unable to make Applied Behavioral Analysis (ABA) subject to visit limits applicable to other therapies. Furthermore, it is assumed that this therapy will be provided by licensed practitioners at specified rates. The consultant considers this combination of assumptions to give a cost estimate which is likely to be on the high side.

However, the Commission notes the possibility that mandated coverage for therapies, particularly ABA could cause adverse selection when people have a choice about whether to become insured. This could result in prevalence of autism in the covered population that is higher than in the population as a whole. This would lead to costs even higher than the consultant's estimate.

Based on the consultant's work and available statistics on the New Jersey Commercial market, DOBI staff estimate that the average cost of insurance coverage could increase by about 0.4% per covered person, or \$47.2 million in total.

A certain number of people, approximately 4,200, might lose coverage solely as a result of the cost increase associated with this mandate. Estimates of the impact of price increases on the purchase of insurance coverage are based on a number of assumptions, and are consequently not precise. This approximation makes assumptions about elasticity (which is the purchaser's response to a valueless increase in price), and assumes that the purchaser assigns no value to the cost increase associated with the mandate.

Because the therapies mandated by this bill are primarily used by children, the impact on rates and coverage that include children (family or parent/child coverages) will probably be disproportionately higher. Children may be more likely to lose coverage, either because employers drop the option of family coverage, or because the employee's share of family coverage becomes too expensive.

The Commission agrees that appropriate forms of early intervention for children diagnosed with Autism Spectrum Disorder (ASD) reduce the impact of symptoms on functioning in later life. There are savings to society as a whole in terms of improved health and ability to learn and function. However, the Commission notes that the current costs of this mandate largely fall on the purchasers of health coverage (employers, employees, and individuals) while society as whole reaps the benefits, especially in reduced costs for public programs for special education and support for the developmentally disabled.

The Commission is aware that school districts in New Jersey have the obligation to provide appropriate early intervention and special education services. These services may include Applied Behavioral Analysis, or services of a similar nature. It is the Commission's general understanding that the level of services provided in this context is held in high regard nationwide. The Commission suggests that the legislature consider whether shifting the provision of some of these services to the commercial insurance system would harm, rather than enhance, the present system. The Commission raises the possibility that an unintended consequence of this bill would be a disruption of the current (highly regarded) public system of addressing autism, by creating disparities in available funding and type of treatment.

The Commission could not find conclusive evidence for the efficacy of Applied Behavioral Analysis in the treatment of ASD compared to other treatment methods. Much of the information available for those dealing with ASD speaks very positively about ABA. The Consultant's report summarizes a lot of this positive information. Health carriers, on the other hand, currently take the position that the efficacy of ABA is not established.

The Commission notes that the bill, as written, refers to the provision of the specified therapies when prescribed or recommended by the covered person's licensed physician. The Commission underscores that the licensed health care practitioner who prescribes or recommends such services may not be a physician. Furthermore, the majority of existing covered health services are provided in the managed care environment, allowing for the possibility of a prospective or concurrent review of the necessity of the covered service. Such review would not be permitted under a strict interpretation of this bill, and hence would result in the provision of the mandated services on a more liberal basis than for other covered services.

While this report was in preparation, the Centers for Disease Control and Prevention (CDC) issued a well-publicized report on the prevalence of ASD. This report shows that New Jersey has a prevalence rate markedly above the national average. This report is discussed in more detail below. However, the Commission does not think that this higher prevalence rate (which was reflected in the cost calculations) argues either in favor of or against this bill.

What A-999 Requires

Assembly Bill 999 applies to the state regulated insurance market and the State Health Benefits Plan (SHBP). The regulated insurance market includes individual and group contracts sold in New Jersey by hospital, medical and health service corporations (e.g. Horizon Blue Cross Blue Shield), individual and group policies sold by insurance companies and contracts issued by

health maintenance organizations (HMOs), including contracts and policies sold in the Individual Health Coverage (IHC) and Small Employer Health (SEH) markets.

Scope

The bill requires plans to which it applies to cover expenses incurred in obtaining physical therapy, speech therapy, occupational therapy, applied behavioral analysis and related therapies for the treatment of Autistic Disorder, Childhood Disintegrative Disorder, Asperger's Disorder, Pervasive Developmental Disorder – not otherwise specified or Rhetts's Syndrome. In this report, we will refer to these 5 diagnoses collectively as Autism Spectrum Disorders. These services must be covered when prescribed or recommended by the covered person's licensed physician. The bill requires the benefit to be provided to the same extent as for any other condition covered by the plan.¹

Autism and Autism Spectrum Disorders

The Division of Family Health Services, Special Child Health and Early Intervention Services, has the following general information on its web site:

"Autism is a biologically-based disorder that affects the development of and functioning of a person verbal and non-verbal communication skills, social interactions and patterns of behavior.

...the majority of children and adults with autism will require a lifetime of supportive services (Holmes 1997). Studies show, however, that early detection and appropriate intervention can have a significant effect on the progress and functioning level of children.

The definition of "autism" has changed little since it was coined by Leo Kanner in 1943, but the terminology used today to describe the disorder has. The terms Pervasive Developmental Disorder, Autism Spectrum Disorder, and Autism all essentially describe the same disorder: significant impairments in the area of socialization, communication, and behavior. The term autism spectrum disorder (ASD) has been widely adopted in the professional literature as it more accurately describes the continuum of symptom severity and is inclusive of people with various diagnoses."²

As this report was being prepared, the U.S. Center for Disease Control (CDC) released a report showing that the prevalence of ASD among 8 year olds in New Jersey was 10.6 per thousand, or about 1 in 100. The national average, shown in the same report, was about 1 in 150. The report could offer no conclusive explanation for why New Jersey had a higher rate. The cost estimates in this report are based on the New Jersey prevalence rate of 10.6 per 1000.

¹ We note that twelve states currently mandate some form of coverage for diagnosis and treatment of Autism Spectrum Disorders, classified as either a "serious emotional disturbance" or a "biologically based mental illness": California, Colorado, Connecticut, Georgia, Hawaii, Illinois, Indiana, Kansas, Kentucky, Louisiana, New Hampshire, and New Jersey.

² <http://www.state.nj.us/health/fhs/documents/autism0904.pdf>

The Current Insurance Market

Approximately 3.2 million people (out of the New Jersey population of over 8.7 million) will be affected by the provisions of this bill. They are the **2.4** million people in the regulated insurance market (including **910,000** in the SEH market and **65,000** in the IHC market) and approximately 800,000 covered by the SHBP. (Note A-999 does not apply to approximately 15,000 people covered under individual basic and essential policies.) The current and proposed mandates have no direct effect on the people covered by the self-funded plans (other than the SHBP), Medicare, Medicaid/Family Care, and the uninsured.

The Current Situation

There are currently state or federal mandates requiring coverage of the medically necessary therapies for Autism Spectrum Disorders. In addition therapies are covered by Medicaid and the various NJ FamilyCare plans. (Medicaid and Family Care coverage are not addressed by A-999.)

Plans provided by employers with more than 50 employees, whether self-funded or insured, are subject to the Federal Mental Health Parity Act of 1996, 42 USC 300gg-5. This act requires that any annual lifetime and dollar limits on mental health coverage be no more restrictive than such limits as applied to medical and surgical coverage. As applied to affected employers, this law does not provide the level of parity contemplated by A-999. Furthermore any plan may be exempted if its plan claim costs would increase by 1% as a result of compliance with the "mandate". In addition, any state or local government plan can elect exemption as the SHBP has done. But, this law does not pre-empt stronger state mandates such as the BBMI mandate described below.

In all insured markets, (large employer, SEH and IHC) and the SHBP, the state Biologically Based Mental Illness (BBMI) mandate, P.L. 1999, c.106, requires carriers to cover biologically based mental illness under the same terms and conditions as any other disease (deductibles, co-payments, and benefit maximums) or so-called full parity. Although the law cites some conditions that must be treated as BBMI, it also requires treatment of uncited conditions that satisfy the definition of "biologically-based". BBMI is defined as a mental or nervous condition that is caused by a biological disorder of the brain and that result in a clinically significant or psychological syndrome or pattern that substantially limits the functioning of the person with the illness, including but not limited to:

- Schizophrenia
- Schizoaffective Disorder
- Major Depressive Disorder
- Bipolar Disorder
- Paranoia and other Psychotic Disorders
- Obsessive-Compulsive Disorder
- Panic Disorder
- Pervasive Developmental Disorder or Autism

Under one interpretation, the proposed bill, A-999, provides no, or minimal, extension of benefits beyond that already provided by the BBMI mandate which is already law. Autism and related disorders qualify as BBMI's. The BBMI mandate requires that all services insured under

the contract be covered to the same extent as any other disease; this would apply specifically to physical therapy, occupational therapy, speech therapy, and applied behavioral analysis and related therapies.

Therefore, other than emphasizing the legislative concern that the BBMI mandate apply strictly in the case of Autism Spectrum Disorders, and that there is a particular concern about specific therapies, the law may have no significant impact.

In particular, the Commission believes that the parity in coverage for physical therapy, speech therapy, and occupational therapy directed by A-999 already exists as a result of enforcement of the BBMI mandate. The BBMI mandate requires these therapies (and any other treatments) to be covered to the same extent as other conditions. N.J.A.C. 11:4-57.3(a) clarifies this mandate to require commercial carriers to provide these therapies even when the purpose of the therapy is not to restore the patient to previous level of functioning (a line of reasoning that could be used to deny coverage for these therapies to a patient with ASD). The Michelletti and Markiewicz decisions, quoted below, extended this requirement to the NJ SHBP, and indirectly validated the reasoning of N.J.A.C. 11:4-57.3.

According to two recent Appellate Division decisions (*In re Micheletti*, 389 N.J. Super. 510 (App. Div. 2007) and *Markiewicz v. State Health Benefits Plan*, 2007 N.J. Super. Lexis 10 (App. Div. 2007), the SHBP must cover treatments for autism and other biologically based mental illnesses for public employees. “Unlike the DOBI, the SHBC has not dealt with coverage for treatment of autism and other BBMIs through the regulatory process, although we have suggested that it do so due to the absence of any regulation delineating what benefits are covered and for which are excluded beyond the minimum specified in N.J.S.A. 52:14-29.” The SHBP rejected the two claims because the therapy would “promote development beyond any level of function previously demonstrated..., and is therefore not covered...”

A survey of the largest commercial carriers in New Jersey confirms that these carriers cover physical therapy, occupational therapy, and speech therapy for people with an ASD diagnosis in accordance with the BBMI mandate.

The status of Behavioral Analysis (ABA) is different because ABA is not as widely understood as Physical, Occupational or Speech Therapy. Therefore, a separate discussion of the Current Situation regarding ABA is appropriate.

What is Applied Behavioral Analysis (ABA)?

“In simple terms, Applied Behavior Analysis (ABA) teaches complex tasks by breaking them down into bite-size pieces that can be learned more easily, with each piece building upon the previous one. Rewards, called “reinforcers” are given for correct responses or behaviors while inappropriate responses are corrected, ignored, or redirected. Precise data on each learning trial is recorded, and adjustments in the educational program are made accordingly.

ABA targets development in many areas of skill, including, but not limited to, attending, imitation, language, social, play, self-help, and academics.

Other terms, such as discrete trial learning and Lovaas therapy, have been used in reference to ABA. Discrete trial training, which breaks down a task and teaches it systematically, is a subset of the ABA program that is often used. The term “Lovaas therapy” comes from Dr. O.

Ovar Lovaas, whose landmark research led to the application of ABA techniques for teaching children with autism. Dr. Lovaas is not the only professional who uses ABA to address Autism, but his name is probably the most recognized.

ABA is a form of behavioral therapy, which has been used to treat many disorders for years with notable success. B.F. Skinner in 1938 called this concept of changing behavior by the response of the teacher “operant conditioning.” If a reinforcer immediately followed a desired behavior, the chances of the behavior being repeated increased. If the reinforcer was taken away, the desired behavior would eventually decrease. The same would apply to negative behavior; it will increase if its [sic] reinforced and decrease if it is ignored.”³

Current Health Coverage Situation (ABA)

ABA is a therapy which may be used in the treatment of ASD. It may not be appropriate for all people with ASD, and it may not be the only effective treatment even when appropriate. At this time, carriers take the position that the effectiveness of ABA is unproven.

Carriers who would be subject to this mandate indicate that ABA for people with ASD would be covered subject to the terms of the BBMI mandate on the same basis as physical, occupational, and speech therapy except that (unlike the previous three therapies) ABA is “experimental and investigational”, that is, its effectiveness is unproven.

While carriers state the reasoning for this characterization of ABA in their Practice Bulletins, we think that there are many in the affected community (people with ASD, their advocates, and providers) who would take another position. This argument is summarized in the section “Effectiveness of ABA” below.

It is reasonable to ask how a characterization by a carrier of any treatment as “experimental or investigative” may be challenged. A decision that a service is experimental or investigational and therefore not covered is considered a utilization management denial that is subject to two levels of internal appeal and then to external appeal pursuant to the Independent Health Care Appeals Program (IHCAP) established under N.J.S.A. 26:2S-12.⁴ See Bulletin OMC-2000-04. Thus if a carrier denies coverage of ABA on the grounds that it is experimental, the decision may be overturned by the IHCAP whose decision is binding on the carrier.

In theory, such carrier positions can also be overturned by rulemaking or statute. The Commission has interpreted the intent of A-999, in explicitly requiring coverage for treatment of ABA [reference to directed by physician], to override any general claim by the carrier that the therapy is “experimental and investigational”. Otherwise, the status of ABA under A-999 would not be substantially different than under present law. Parity does not require the coverage of a therapy considered experimental or investigational.

³ Document prepared by Nebraska Parents Center (US Dept. of Education Grant H029M10010) and distributed by PTI Nebraska.

⁴ See Bulletin OMC-2004-04 issued by the Office of Managed Care, New Jersey Department of Health and Human Services, August 15, 2000.

Effectiveness of ABA

It is difficult to summarize the conflicting opinions on the effectiveness of ABA. A cursory review of literature directed at educators, parents, and other advocates for children with autism would leave the impression that ABA, in the general sense of on-going interaction with the child with the goal of modifying behavior to build necessary skills and reduce undesirable behaviors is both widely recommended and practiced. The commencement of a program of this general nature at an early age is one of the reasons commonly given for the need for early diagnosis of ASD. Even health carriers, in their Bulletins outlining the basis for finding ABA to be experimental and investigational, admit that this sort of program, delivered in the education and other settings, is indicated.

Evidence for the use of ABA includes the 1987 UCLA study by Lovaas, which showed improvement in many children receiving the therapy (see fn 14 of the consultant's report), a Minnesota law which provides significant state funding of ABA children diagnosed with ADS⁵, and the decision (in 2001) by Microsoft to include coverage of ABA in its employee health benefit plan⁶. The Consultant's report cites references that are often used to support the effectiveness of ABA.

However, carrier review of the existing data, as evidenced in their practice bulletins, is that the evidence for ABA therapy, especially using the specific principles outlined by Lovaas, has not been shown to be superior to other techniques of training that are less formal and less reliant on professionals⁷.

With limited resources and expertise, this Commission cannot opine on the question of whether or under what circumstances ABA is an effective treatment compared to other treatment modalities.

Qualitative Impact of A-999

The Commission does not believe that A-999 materially extends coverage for physical therapy, speech therapy, and occupational therapy. The BBMI mandate already requires these therapies to be covered to the same extent as other conditions. N.J.A.C. 11:4-57.3(a) clarifies this mandate to require commercial carriers to provide these therapies even when the purpose of the therapy is not to restore the patient to previous level of functioning (a line of reasoning that could be used to deny coverage for these therapies to a patient with ASD.) The Michelletti and Markiewicz decisions extended this requirement to the NJ SHBP, and indirectly validated the reasoning of N.J.A.C. 11:4-57.3. It should be noted, however, that carriers are not required to cover physical therapy, speech therapy, and occupational therapy for any condition.

The Commission believes that the impact of the requirement that ABA and related therapies be covered could be significant. Currently, despite the BBMI mandate, claims for ABA do not appear to be routinely reimbursed by commercial carriers. The stated reason is that the therapy is experimental and investigational, that is, that its effectiveness is unproven.

The bill states that ABA is to be covered to the same extent as treatment for any other condition. However, any other condition is only covered to the extent that it is performed by a

⁵ Minnesota Statutes 2001, section 256B.0625, Subd. 5a:

⁶ Behavioral Analysis Association of Michigan, BAAM-ASIG News, Vol. 1, #1, Sept. 2001, "Microsoft 1st National US Corporation to Cover ABA Treatment for Autism". p.6

⁷ For example, Aetna's policy at www.aetna.com/cpb/medical/data/600_699/0648.html

licensed practitioner. Carriers may establish standards for the therapists who will perform the ABA, and this may limit the impact.

The Commission also notes that the treatment must be covered when prescribed by the covered person's licensed physician. Taken literally, this provision would override the pre-authorization and other utilization management procedures that are part of managed care plans. The amount of covered services provided might increase. On the other hand, the requirement of a "licensed physician" is probably unduly limiting because other licensed health care practitioners are capable of evaluating the need for ABA and other therapies.

Finally, some ABA may currently *be* provided in the pre-educational and educational setting, through mandated early intervention and special education programs. It is not clear to the Commission if the intent of the law is to mandate the coverage of ABA provided in addition to that required to be provided by the education system, or if the intent is for the carriers to pay for such therapy. The Commission raises the possibility that an unintended consequence of this bill would be a disruption of the current (highly regarded) public system of addressing autism, by creating disparities in available funding and type of treatment.

Positive Effects of the Mandate

The therapies enumerated in the bill (physical, speech, and occupational therapy as well as ABA or related therapies) are generally seen as improving the life prospects of the person with ASD. (As noted several places in this report, health carriers question whether the particular approach of ABA, as opposed to a more general training approach, is effective.) The term "quality of life" is probably not appropriate here, because it diminishes the fact that effective intervention may be the difference between institutionalization or living in the community, or the level of financial and social independence which can be attained. These issues affect, of course, the family and community as well as the person.

Several sources argue that the cost benefit equation of early therapy, including ABA, is compelling, with each dollar spent on therapy repaid many times over in societal savings from greater independence and reduced social services expenditures. Even granting that this is true, however, the costs in the case of this mandate are imposed upon the commercial carriers (and their premium payers) while the benefits of reduced social services accrue to society, particularly taxpayers, as a whole.

Impact on Premiums of A-999

The actuarial consultant evaluated the cost impact of the proposed mandate on health care premiums. The consultant concluded that it is likely that the impact will be largely on family premiums, rather than overall premiums. The impact on a family premium is about .79%, and would increase the family premium by about \$10.17 per month.

As a dollar amount, DOBI staff estimated premium increase (based on the work of the consultant) is about \$ 47.2 million, about .44% of total estimated commercial market premium of 10.8 billion. (This excludes the impact on the SHBP.)

Impact on Purchase of Coverage

The DOBI staff estimate (.44% increase in premium) assumes that the increase in medical costs associated with this mandate is directly reflected in the premium. This is a reasonable assumption. However, carriers for competitive or other reasons may not necessarily reflect the entire cost of the mandated benefit in the premium. In that case, the premium increase would be lower.

The additional cost associated with A-999 is largely for the children's coverage. Therefore, carriers may increase premiums for family coverage (including parent/children coverage) more than coverage for adults.

Generally, increases in premiums cause some policyholders to drop insurance coverage. The extent to which an increase in premium causes a decrease in coverage cannot be precisely measured, and depends in part on the reason for the cost increase. In general, premium payers react differently to a price increase that reflects additional benefits than to a price increase that does not do so.

The term "elasticity" refers to the response of purchasers to a small price change. For example, if the elasticity for health coverage is -0.5, each 1% increase in premium will cause 0.5% of policyholders to drop coverage. -0.4 is generally accepted a reasonable measure of elasticity for health coverage.

Using a population subject to the mandate of 2.4 million (3.3 million less the 800,000 in the SHBP), the cost impact of .43 %, an elasticity of -0.4, 4,224 people would be estimated to drop coverage as a result of the cost increase arising from this mandate.

There is also a possibility of adverse selection if there is significant coverage for ABA. This is especially likely in the Individual and Small Employer Market. Adverse selection can occur when the premium for insurance coverage is significantly less than the known or expected loss. In this case, people with a high possibility of an ASD diagnosis have an incentive to enroll. Pre-existing condition exclusions would have limited effectiveness.

Impact on the Affordability and Utilization of ABA

It is reasonable to conclude that the use of Applied Behavioral Analysis will increase to the extent that insurance coverage makes affordable a treatment that would not otherwise be so. Furthermore, covered treatments that would have been otherwise purchased will be more affordable due to insurance coverage. The covered person would otherwise have to use his/her own funds to undergo the needed treatment.

It is commonly accepted that insurance coverage of a treatment tends to drive up the price of the treatment. Moreover, insurance coverage may result in increased treatment.

It is our impression that the number of licensed practitioners to provide ABA is limited. One positive effect of this mandate may be to draw additional people into the field, and to provide incentives for upgraded training and certification. Supervision and evaluation of techniques may also improve.



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A Report to the New Jersey Mandated Health Benefits Advisory Commission

***Review and Evaluation of Assembly Bill A999
An Act Concerning Health Benefits Coverage for Certain
Therapies and Applied Behavioral Analysis for the
Treatment of Certain Autism Disorders.***

February 2007

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Background and Conclusion

The New Jersey Legislature has requested the New Jersey Mandated Health Benefits Advisory Commission to conduct a review of Assembly Bill 999 (A999), a bill that requires all health carriers to cover necessary expenses incurred when the covered person's primary diagnosis is Autistic Disorder, Childhood Disintegrative Disorder, Asperger's Disorder, Pervasive Developmental Disorder - Not Otherwise Specified or Rhett's Syndrome. Expenses to be covered include those for: physical therapy; speech therapy; occupational therapy; and behavioral interventions based on principles of applied behavioral analysis and related structured behavioral programs. The review was conducted using the requirements stipulated under the Mandated Health Benefits Advisory Commission Act, N.J.S.A. 17B:27D-1 et seq.

Considering the limited time and expertise of the Commission and Department staff, an actuarial firm, NovaRest Consulting, with experience in such investigations was engaged to study this matter and to prepare a report addressing all of those facets.

The Commission understands that the Legislature specifically desires a discussion of the implications of this bill on the insurance market, including impact on price and on the availability of necessary medical services.

We believe that the assumptions in developing our estimate overstate the cost of ABA and represent a maximum cost scenario. This maximum cost would only be reached over time as ABA becomes more widely used. Until ABA is common practice, the cost would only be a fraction of this estimate. Using these assumptions, we estimate the cost per child being treated under the age of 5 as \$50,787 per year and over the age of 5 as \$33,858. Using assumption on the age of commencement of treatment, we estimate the cost to be of \$72 per year per insured child, which represents approximately 0.8% of family premium and 2.1% of child only premium.

What A999 Requires

As specified in A999 it requires that every individual and group hospital service corporation contract that provides hospital and medical expense benefits and is delivered, issued, executed or renewed in this State pursuant to P.L.1938, c.366 (C.17:48-1 et seq.), or approved for issuance or renewal in this State by the Commissioner of Banking and Insurance, on or after the effective date of this act, shall, when the covered person's primary diagnosis is Autistic Disorder, Childhood Disintegrative Disorder, Asperger's Disorder, Pervasive Developmental Disorder - Not Otherwise Specified or Rhett's Syndrome, provide coverage for expenses incurred for the following treatments when prescribed as



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medically necessary by the covered person's physician: physical therapy; speech therapy; occupational therapy; and behavioral interventions based on the principles of applied behavioral analysis and related structured behavioral programs. ... The benefits shall be provided to the same extent as for any other medical condition under the contract. The provisions of this section shall apply to all contracts in which the hospital service corporation has reserved the right to change the premium. Each contract shall, provide coverage for expenses incurred for the following treatments when prescribed as medically necessary by the covered person's physician:

- physical therapy;
- speech therapy;
- occupational therapy; and
- behavioral interventions based on the principles of applied behavioral analysis and related structured behavioral programs.

The benefits shall be provided to the same extent as for any other medical condition under the contract.

As stated above, the bill requires plans to which it applies to cover expenses incurred in obtaining physical therapy, speech therapy, occupational therapy, applied behavioral analysis and related therapies for the treatment of Autistic Disorder, Childhood Disintegrative Disorder, Asperger's Disorder, Pervasive Developmental Disorder – not otherwise specified or Rhetts Syndrome. In this report, we will refer to these 5 diagnoses, which are collectively known as Autism Spectrum Disorder (ASD) by the commonly used name of autism.

What is Autism

Autism is a developmental disability that typically involves delays and impairment in social skills, language, and behavior. Autism is a spectrum disorder, meaning that people diagnosed as autistic have varying levels of severity. Some children may have speech capabilities, whereas others may have little or no speech capability. Less severe cases may be diagnosed with Pervasive Developmental Disorder (PDD) or with Asperger's Syndrome (these children typically have normal speech, but they have many "autistic" social and behavioral problems).

Left untreated, many autistic children will not develop effective social skills and may not learn to talk or behave appropriately. Very few individuals progress along the autism spectrum without any intervention.

Previously it was estimated that autism affects two to six of every 1,000 people¹, but more recent studies have increased that estimate to 1 in every 150. This

¹ Centers of Disease Control and Prevention (2001)



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study reports that in New Jersey autism affects 10.6 of every 1,000 births². It is currently the fastest growing developmental disability with a 10-17% annual growth rate³. While the US population increased by 13% during the 1990s, autism increased by 172%⁴.

Economic Cost of Autism

It is estimated that the annual cost of autism is \$90 billion per year, with 90% of the costs being for adult services⁵. In ten years, it is estimated that the annual cost will increase to \$200-400 billion⁶. It is further estimated that the cost of life long care can be reduced by 2/3 with early diagnosis and intervention⁷.

The Canadian Broadcasting System (CBC) in a recent program entitled "The Nature of Things" estimated the lifetime cost of supporting an untreated autistic child is at least \$1.7 million, not including opportunity cost or even lost tax revenues. Life long opportunity cost has been estimated at an additional \$1,276,000⁸. Based on these estimates, using an average lifespan of 75 years, the annual cost per untreated person with autism is \$39,503.

Lifespire Inc. (formerly the Association for Children with Retarded Medical Development – NY, NJ) has estimated the annual costs for an autistic disabled adult to be \$225,000. The lifespan costs based on a 45 year adult life span (to age 66 – conservative estimate of lifespan based on actuarial tables) to be \$10,125,000. These estimates do not include any costs for the period up to and including age 21!

In addition to the direct costs of autism, there may be many secondary costs not included in these estimates. Anecdotally, many marriages founder from the stress of raising a severely disabled child. Demand for family support is likely to be increased. Longevity might be compromised. Studies⁹ have shown that family members of individuals with autism have depression, anxiety disorders or the extended phenotype – the first two may be exacerbated by the stress of

² CDC Releases New Data on Autism Spectrum Disorders (ASDs) from Multiple Communities in the United States
(<http://www.cdc.gov/od/oc/media/pressrel/2007/r070208.htm>)

³ Autism Society of America

⁴ U.S. Department of Education's "Twenty-First Annual Report to Congress on Implementation of Individuals with Disabilities Education Act" (1999)

⁵ Jarbrink K Knapp M, 2001, London School of Economics study: "The economic impact of autism in Britain," 5 (1): 7-22

⁶ Autism Society of America calculation, February 2003.

⁷ Jarbrink K Knapp M, 2001, London School of Economics study: "The economic impact of autism in Britain," 5 (1): 7-22

⁸ www.jackiebarrett.ca/june2003.htm

⁹ J. Pivan et al., 1997



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caring for a disabled child and may impede the search for implementation of interventions; the second could reduce the total family resources for earning.

Treatment of Autism

There is no single best treatment package for all children with autism. One point that most professionals agree on is that early intervention is important; another is that most individuals with autism respond well to highly structured, specialized programs.

Treatment depends on the individual needs of the patient. In most cases, a combination of treatment methods is more effective. Occupational therapy and physical therapy are sometimes used to treat autism. Occupational therapy helps improve independence and teaches basic skills (e.g., buttoning a shirt, bathing). Physical therapy involves using exercise and other physical measures (e.g., massage, heat) to help patients control body movements. Communication therapy is used to treat autistic patients who are unable to communicate verbally, or to initiate language development in young children with the disorder. Speech therapy may be used to help patients gain the ability to speak.

Behavior modification is one of the most effective courses of treatment for autism. There are several methods of behavior modification that are used to treat inappropriate, repetitive, and aggressive behavior and to provide autistic patients with skills necessary to function in their environment. Most types of behavior modification are based on the theory that rewarded behavior is more likely to be repeated than behavior that is ignored. This theory is called applied behavior analysis (ABA), which is addressed extensively later on in this report.

Behavior modification often involves highly structured, skill-oriented activities that are based on the patient's needs and interests. It usually requires intense, one-on-one training with a therapist and extensive caregiver involvement.

An effective treatment program will build on the child's interests, offer a predictable schedule, teach tasks as a series of simple steps, actively engage the child's attention in highly structured activities, and provide regular reinforcement of behavior. Parental involvement has emerged as a major factor in treatment success. Parents work with teachers and therapists to identify the behaviors to be changed and the skills to be taught. Recognizing that parents are the child's earliest teachers, more programs are beginning to train parents to continue the therapy at home.

As soon as a child's autism has been diagnosed, instruction should begin. Effective programs will teach early communication and social interaction skills. In children younger than three years of age, appropriate interventions usually take



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place in the home or a childcare center. These interventions target specific deficits in learning, language, imitation, attention, motivation, compliance, and initiative of interaction. Included are behavioral methods, speech, occupational and physical therapy along with social play interventions. Often the day will begin with a physical activity to help develop coordination and body awareness; children string beads, piece puzzles together, paint, and participate in other motor skills activities. At snack time, the teacher encourages social interaction and models how to use language to ask for more food and juice. The children learn by doing. Working with the children are students, behavioral therapists, and parents who have received extensive training. In teaching the children, positive reinforcement is used.¹⁰

Children older than three years of age usually have school-based, individualized, special education. The child may be in a segregated class with other autistic children or in an integrated class with children without disabilities for at least part of the day. Different localities may use differing methods but all should provide a structure that will help the children learn social skills and functional communication. In these programs, teachers often involve the parents, giving useful advice in how to help their child use the skills or behaviors learned at school when they are at home.¹¹

In elementary school, the child should receive help in any skill area that is delayed and, at the same time, be encouraged to grow in his or her areas of strength. Ideally, the curriculum should be adapted to the individual child's needs. Many schools today have an inclusion program in which the child is in a regular classroom for most of the day, with special instruction for a part of the day. This instruction should include such skills as learning how to act in social situations and in making friends. Although higher-functioning children may be able to handle academic work, they also may require help to organize tasks and avoid distractions.

During middle and high school years, instruction will begin to address such practical matters as work, community living, and recreational activities. This should include work experience, using public transportation, and learning skills that will be important in community living.¹²

¹⁰ Couper JJ, Sampson AJ. Children with autism deserve evidence-based intervention. *Medical Journal of Australia*, 2003; 178: 424-425.

¹¹ American Academy of Pediatrics Committee on Children With Disabilities. The pediatrician's role in the diagnosis and management of autistic spectrum disorder in children. *Pediatrics*, 2001; 107(5): 1221-1226.

¹² Dunlap G, Foxe L. Teaching students with autism. *ERIC EC Digest* #E582, 1999 October.



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Applied Behavior Analysis (ABA) - Among the many methods available for treatment and education of people with autism, applied behavior analysis (ABA) has become widely accepted as an effective treatment. *Mental Health: A Report of the Surgeon General* states, "Thirty years of research demonstrated the efficacy of applied behavioral methods in reducing inappropriate behavior and in increasing communication, learning, and appropriate social behavior."¹³ The basic research done by Ivar Lovaas and his colleagues at the University of California, Los Angeles (UCLA), calls for an intensive, one-on-one child-teacher interaction for 40 hours per week, laid a foundation for other educators and researchers in the search for further effective early interventions to help those with ASD attain their potential. The goal of behavioral management is to reinforce desirable behaviors and reduce undesirable ones.^{14 15}

Many different behavioral interventions have been developed for children with autism, and they mostly fall under the category of ABA. This approach generally involves therapists who work intensely, one-on-one with a child for 20 to 40 hours/week. Children are taught skills in a simple step-by-step manner, such as teaching colors one at a time. The sessions usually begin with formal, structured drills, such as learning to point to a color when its name is given; and then, after some time, there is a shift towards generalizing skills to other situations and environments. A study published by Dr. Ivar Lovaas at UCLA in 1987¹⁶ involved two years of intensive, 40-hour/week behavioral intervention by trained graduate students working with 19 young autistic children ranging from 35 to 41 months of age. Among the group of children studied, 47% improved so much that they were indistinguishable from typical children, requiring no specialized services after entering elementary school. An additional 42% had significant improvements. ABA programs are most effective when started early, (before five years of age), but they can also be helpful to older children. They are especially effective in teaching non-verbal children how to talk.

The research for intensive, early behavioral treatment which resulted in some children testing within the normal range on IQ, adaptive skills, and social skills, had children start treatment typically between the ages of two and three-and-a-half. On the other hand, there have been over 100 research articles

¹³ Department of Health and Human Services. *Mental Health: A Report of the Surgeon General*. Rockville, MD: Department of Health and Human Services, Substance Abuse and Mental Health Services Administration, Center for Mental Health Services, National Institute of Mental Health, 1999.

¹⁴ Lovaas OI. Behavioral treatment and normal educational and intellectual functioning in young autistic children. *Journal of Consulting and Clinical Psychology*, 1987; 55: 3-9.

¹⁵ McEachin JJ, Smith T, Lovaas OI. Long-term outcome for children with autism who received early intensive behavioral treatment. *American Journal on Mental Retardation*, 1993; 97: 359-372.

¹⁶ Lovaas, 1987; McEachin, Smith, & Lovaas 1993



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documenting the use of applied behavior analysis principles to teach new skills to children with autism over the age of five. Most of these studies were not comprehensive programs, but rather focused on one issue (e.g., one skill to develop or one behavior to change). Beyond efficacious treatment of autistic people, research shows, by the way, that ABA procedures have been used effectively in many intervention programs to address the needs of a variety of populations and diagnoses (e.g., teaching children to read, helping adults quit smoking, increasing productivity of a business, etc.).

The National Research Council's 2001 book *Educating Children with Autism* discusses interventions for adolescents and adults. The book points out, "A number of interventions have demonstrated that adolescents or adults with autism can be taught purchasing skills and other community living skills, such as ordering food in a restaurant (Haring et al., 1987). However, most applications of instruction in community living skills have been developed for children and adults with mental retardation. Daily living skills targeted have ranged from appropriate mealtime behaviors (O'Brien et al., 1972; Wilson et al., 1984), to eating in public places (van den Pol et al., 1981). Proactive approaches to promoting community access include instruction in clothing selection skills (Nutter and Reid, 1978), pedestrian safety (Page et al., 1976), nondisruptive bus riding (Neef et al., 1978), vending machine use (Sprague and Horner, 1984), and coin summation (Lowe and Cuvo, 1976; Miller et al., 1977; Trace et al., 1977). Additionally, procedures for teaching leisure skills have targeted independent walking (Gruber et al., 1979) and soccer (Luyben et al., 1986)."

The vast majority of these interventions are behavioral interventions. Most citations are from the *Journal of Applied Behavior Analysis*. While much attention has been paid to the young children who made phenomenal progress in early, intensive behavioral treatment, such research does not exhaust the benefits of such treatment. Therapy utilizing ABA is primarily meant to improve the quality of life of an individual with autism. This can be accomplished in early childhood, adolescence, and even later in life.

Impact on Premiums of A999

A999 requires health plans to cover specific services for the treatment of autism. These services include:

- physical therapy;
- speech therapy;
- occupational therapy; and
- behavioral interventions based on the principles of applied behavioral analysis (ABA) and related structured behavioral programs.

Our research indicates that all of the above services are currently covered by health plans with the exception of ABA. We therefore only consider the cost of



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ABA in our analysis of the additional cost to health plans and therefore the insured population.

Estimates vary on the cost of ABA treatments and the use of ABA after childhood. Treatment is best started as early as possible after diagnosis and continues for 3-5 years. This would imply that much of the therapy is prior to school age. If treatment starts at 1 ½ to 5 years of age an average of 1 ½ years of the three to five year treatment would be completed prior to kindergarten. The later the treatment is started, the more of the treatment would continue into the school years. No estimates were found of precise changes in therapy intensity when children go to school.

Based on an analysis of the new autism law in Minnesota¹⁷ and estimates of the recommended hours per week of therapy we have estimated that ABA treatment would be \$50,787 per year for children that are receiving 30 hours a week of therapy. This is based on a distribution of hours by provider type and estimated charges per hour. Therapy is estimated to take 20-40 hours and some sources recommended a minimum of 25 hours so we used 30 hours a week for 52 weeks. This estimate is expected to be on the high side based on the realities of scheduling children with holidays, vacations, and miscellaneous sick days.

Children under age five would be expected to receive a higher number of hours of therapy per week. However, at kindergarten age, we would expect the children that had previously been in an ABA therapy program to split their time between normal school activities and therapy. In the absence of information we used an estimate of 20 hours a week once children were in school.

Although adults can benefit from ABA, it is typically only used for specific activities of life¹⁸ and we assumed that the treatment in adults would be minimal and most likely combined with other treatments.

In New Jersey, children under the age of five represent 25% of children¹⁹ and children ages five to nine years old represent 26.5% of children. The percentage of children with autism is estimated to be 0.6%. Not all autistic children under age 10 will receive ABA treatment even if it is covered by insurance. We used an estimate of 85% receiving treatment. Children that begin treatment starting at

¹⁷ Summary of the New Autism Law in Minnesota; Eric Larsson

¹⁸ Census data at

"http://factfinder.census.gov/servlet/QTable?_bm=n&_lang=en&q_r_name=DEC_2000_SF1_U_DP1&ds_name=DEC_2000_SF1_U&geo_id=04000US34"

¹⁹ For our estimates, we defined a child to be a person under the age of 20. This was a simplifying assumption used, because we had population statistics broken at age 20. This will cause some mathematical error since children are typically insured until age 18 unless they continue in school, in which case they are insured until age 23.



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age three to five for the recommended three to five years will have completed their treatment by age 10. We recognize that this is over-simplifying the reality of when children will begin therapy, the number of years of therapy, and the intensity of the therapy, but we believe that many of these factors will be offsetting.

We believe that the assumptions used above overstate the cost of ABA therapy and represent a maximum cost scenario. This maximum cost would likely only be reached over time as ABA becomes more widely used. Until ABA is more common practice, the cost would only be a fraction of this estimate. Using these assumptions, we estimate the cost per child being treated under the age of 5 as \$50,787 per year and over the age of five as \$33,858 per year. Using assumption on the age of commencement of treatment, we estimate the cost to be \$72 per year per insured child, which represents approximately 0.5% of family premium²⁰ and 2.1% of child only²¹ premium.

²⁰ Medical Expenditure Panel Expenditure Panel Survey (MEPS) for New Jersey 2004

²¹ Estimate of current child premium received from the New Jersey Department of Banking and Insurance