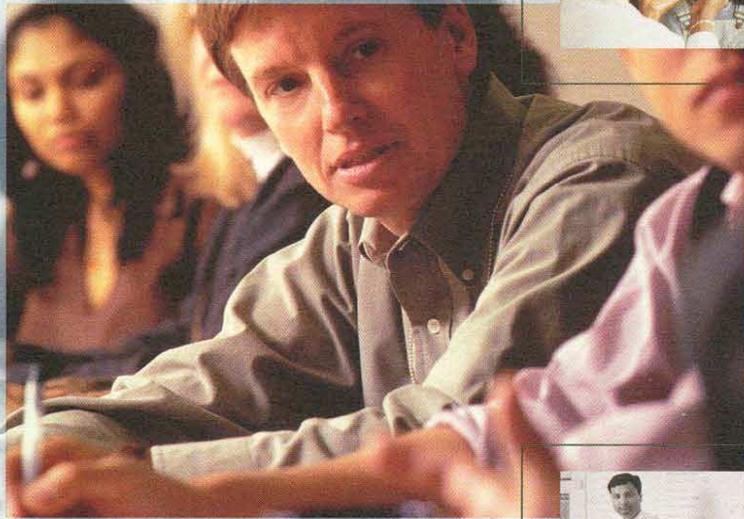
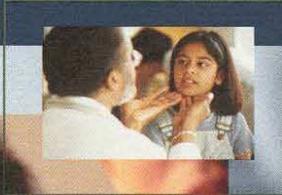


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Abt Associates Inc.

**Autism Spectrum Disorders
Mandated Benefits Review
Panel Report:**

**Evidence Submitted
Concerning Pennsylvania
HB 1150**

Contract No. SP-370331

June 18, 2008

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Evidence Submitted Concerning Pennsylvania HB 1150**

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Autism Spectrum Disorders Mandated Benefits Review for Pennsylvania House Bill 1150

Introduction

This is the report of findings by the Mandated Benefits Review Panel for Pennsylvania's HB 1150, which mandates coverage for the diagnosis and treatment of autism spectrum disorders (ASD) for children under the age of 21. The Pennsylvania Health Care Cost Containment Council (PHC4), acting in accordance with Section 9 of Pennsylvania's Health Care Cost Containment Act (Act 14 of 2003), issued Request for Proposals (RFP) 2008-1 in January, 2008, for a Panel to conduct an independent scientific review of the evidence submitted concerning HB 1150. The Panel was selected on the basis of competitive peer review of proposals submitted in response to the RFP, which resulted in selection of the proposal submitted by Abt Associates, Inc. (Abt).

Per the RFP and as mandated by Act 14 of 2003, the Panel includes five specific types of expertise: (1) health research, (2) biostatistics, (3) economics research, (4) insurance or actuarial research, and (5) physician with experience in autism care. The RFP's charge to the Panel was specific: review and evaluate independently the all evidence submitted by diverse stakeholders in support of or opposition to the benefit mandate.

The RFP was also specific about the structure and content of the Panel's report—the report was to address eight specific questions about the submitted evidence. In addition, it required the Panel to report whether: the research cited in the submitted evidence meets professional standards; all relevant research regarding the proposed mandated benefit has been included in the evidence; and whether any conclusions and interpretations included in the submissions are consistent with the evidence submitted.

PHC4 staff provided Abt with paper copies of all evidence submitted concerning HB 1150. Multiple stakeholder groups were represented among those who submitted evidence, including: more than 40 letters from parents and other family members; 8 ASD advocacy groups; 7 insurers or their representatives; 8 service providers; 2 Pennsylvania state agencies (Departments of Insurance and Public Welfare); and 19 individual Pennsylvania legislators (14 Representatives, including Speaker Dennis O'Brien, and 5 Senators). Evidence included in these diverse submissions ranged across the full spectrum of empirical bases, including anecdotal descriptions of specific cases, natural history studies of convenience samples, records-based studies of service utilization and/or cost, quasi-experimental comparisons of groups who received differing treatment regimens, and randomized, controlled trials (RCT) of the efficacy of specific interventions. In addition, some arguments included in the submissions were based on concepts and/or logic for which no empirical basis was provided.

In what follows, the Panel provides answers to the eight specific questions concerning the submitted evidence that were posed in the RFP, based on our review and evaluation of that evidence.

Question1. The extent to which the proposed benefit and the services it would provide are needed by, available to and utilized by the population of the Commonwealth.

Autism and the other ASDs are biomedical brain disorders.¹ The severity of these disorders varies along a continuum, with some individuals having more profound problems in one key diagnostic area than others, and is associated with the full range of cognitive abilities. As is true of many other biomedical disorders, there is currently no cure for autism. Rather, autism care is focused on controlling or diminishing symptoms and associated impairments. In this way it does not differ from numerous other chronic medical disorders whose treatment is covered routinely by health insurance, including hypertension, diabetes, renal failure, and asthma. Additionally, there is evidence that a number of diverse treatments can lead to improved functioning in autism even though they do not lead to a cure. Like many other medical conditions these treatments include non-pharmacologic approaches. For instance, exercise, general diet and avoidance of environmental factors such as salt and concentrated sugars are considered to be key elements of the management of hypertension and diabetes. Very often these treatments lead to markedly improved function, even though the core disorder remains.

Extent of need. Multiple strands of the submitted evidence support the fact that ASD-related services are needed by significant numbers of Pennsylvania (PA) children. Because ASDs are chronic, disabling disorders, by definition *all* children who meet the diagnostic criteria for ASDs have important health and related needs. Recent evidence from multiple epidemiologic studies, including two of those submitted^{2,3} points to a population prevalence of ASDs of about 1 per 150 children. In addition, some evidence suggests that the population prevalence has been rising in recent decades, but differences in study methods, diagnostic criteria for ASD, and increased attention to ASD can not be ruled out as accounting for some or all of the apparent increase³. Regardless, it is clear that a substantial number of PA children suffer from ASDs, and there is little reason to believe that the true prevalence of ASDs among children in PA differs much from that estimated in the recent studies (e.g., CDC’s recent multisite epidemiologic study³ that included 16 independent communities documented a cross-community range of prevalence estimates from 3.3 to 10.6 per thousand 8 year olds, and noted that most of the community estimates fell in the range 5.2 to 7.6 per thousand).

¹ This is a clearly established fact. It is also stated in several of the pieces of evidence submitted such as the autism fact sheet from the National Institute for Child Health and Human Development which states “Autism is a complex neurobiological disorder” and from Volkmar F, Pauls D, 2003. Autism. The Lancet 362:1133-1141. stating, “Autism is a neuropsychiatric disorder”.

² Frombonne E, 2005. Epidemiology of autistic disorder and other pervasive developmental disorders. Journal of Clinical Psychiatry 66(suppl 10):3-8.

³ CDC Autism and Developmental Disabilities Monitoring Network Surveillance Year 2002 Principal Investigators, 2007. Prevalence of Autism Spectrum Disorders—Autism and Developmental Disabilities Monitoring Network Surveillance, 14 sites, United States, 2002. Morbidity and Mortality Weekly Report 56/SS-1:12-28

More specifically, given the size of the PA population, with 3.2 million children between ages 2 and 20 and applying the current prevalence estimates, there are approximately 21,300 children in PA with autism, who therefore need medical and other care.⁴ However, given the rate of self-insurance which is not subject to the mandate (~44%) and uninsured (~1.5%),⁵ more than 10,337 PA children would likely be eligible to benefit from HB1150. It should be noted that the estimated prevalence of children in PA with autism (21,300) is significantly greater than the 13,800 identified as currently being served by the Department of Public Welfare (DPW).⁶

In summary, the evidence submitted and the clinical experience of the Panel's autism physician are consistent in indicating that there is clear need for medical treatment of PA children who have ASDs.

Access to needed services. Although the submitted evidence documents that many services for children with ASDs exist in PA, it also identifies important barriers that reduce access to those services. Personal experiences described by parents and other family members, along with materials submitted by legislators, PA state agencies,⁷ and an independent report by the Pennsylvania Autism Task Force,⁸ document that Pennsylvania's Medicaid program—DPW's Medical Assistance (MA) program—is fragmented, does not cover all of those in need, and has inadequate payment schedules for at least some providers and/or specific services.

The evidence submitted also documents, however, that some 13,800 PA children with ASDs *are* currently receiving services under the MA program,⁶ but by subtraction of the above estimates an estimated 7,500 are not. The anecdotal evidence alone documents at least some children with severe impairments do not receive the care required to reduce their impairments.

Additionally, substantial evidence in the scientific and medical literature that was included in the submissions documents that early detection and intervention are critical to the ultimate functioning level of people with ASDs, underscoring the importance of the mandated benefit's focus on providing care for children under age 21.⁹ There is broad consensus across the

⁴ From Joel Ario, PA Insurance Commissioner letter of 3-6-08, page 2, 3rd full paragraph, citing U.S. Bureau of Census, Table DP-1, Profile of General Demographic Characteristics: 2000. Census 2000, at <http://censtats.census.gov/data/PA/04042.pdf>. These estimates are consistent with the www.census.gov/population/projections/state/stpage.txt reports for July 2005.

⁵ The Insurance Federation of Pennsylvania letter of 10-4-07 citing 2003 Medical Expenditure Panel Survey taken by the federal Department of Health and Human Services Agency for Healthcare Research & Quality, page 5 5th full paragraph.

⁶ Joel Ario, PA Insurance Commissioner letter of 3-6-08, page 2, 3rd full paragraph.

⁷ Estelle Richman, Secretary of DPW's letter of 11-19-07, pages 6-7 and 10-12.

⁸ Slide presentation entitled Bureau of Autism Services Department of Public Welfare Update, April 3, 2007.

⁹ There were too many pieces of submitted evidence attesting to this to list all of them, but examples include Bryson SE, Rogers SJ, Frombonne E, 2003. Autism spectrum disorders: early detection, intervention, education, and psychopharmacological intervention. *Canadian Journal of Psychiatry*, 48: 506-516; Rogers, SJ, 1998. Empirically supported comprehensive treatments for young children with

medical and other fields that provide care to children with ASDs (e.g., pediatrics, psychiatry, neurology and the allied fields of psychology, speech therapy, occupational therapy and physical therapy) that the best and most efficacious treatment of autism requires early recognition and diagnosis and early intensive treatment while the brain has the maximum potential to recover and/or compensate for the underlying pathophysiologic processes. Intensive remediation through repeated appropriate behaviors in affected brain processes (communication, social responsiveness, sensory processing), which is analogous to physical therapy for victims of stroke or nerve damage, is very widely accepted as a critical element in the treatment of autism. The submitted evidence supporting this point is too numerous to list in their entirety but include the National Institute of Child Health and Human Development Autism Overview:

“Research shows that early diagnosis and interventions delivered early in life, such as in the preschool period, are more likely to result in major positive effects on later skills and symptoms. . . . Because a young child’s brain is still forming, early intervention gives children the best start possible and best chance of developing their full potential. Even so . . . it’s never too late to benefit from treatment. People of all ages with ASDs at all levels of ability generally respond positively to well designed interventions.”¹⁰

Trials of such remediation have consistently demonstrated significant improvements in symptoms over periods of months to 2-3 years. ¹¹

The efficacy of pharmacologic interventions appears to be less robust.¹² At present, only risperidone has been demonstrated to be widely efficacious in reducing mood lability, self injurious behaviors and aggression that often interfere with progress in the core areas of the

autism. *Journal of Clinical Child Psychology* 27:168-179; New York State Department of Health, Clinical Practice Guideline, Report of the Recommendations Autism/Pervasive Developmental Disorders 1999; publication no 4215 and Clinical Practice Guideline: The Guideline Technical Report, 1999; Volkmar F, Pauls D, 2003. *Autism. The Lancet* 362:1133-1141.

¹⁰ The submitted evidence supporting this point are too numerous to list in their entirety but include National Institute of Child Health and Human Development Autism Overview “Research shows that early diagnosis and interventions delivered early in life, such as in the preschool period, are more likely to result in major positive effects on later skills and symptoms. . . . Because a young child’s brain is still forming, early intervention gives children the best start possible and best chance of developing their full potential. Even so . . . it’s never too late to benefit from treatment. People of all ages with ASDs at all levels of ability generally respond positively to well designed interventions.”

¹¹ Harris SJ, Delmolina L, 2002. Applied behavioral analysis: its application in the treatment of autism and related disorders in young children. *Infants and Young Children* 14:11-17.; Rogers SJ, 1998. Empirically supported comprehensive treatments for young children with autism. *Journal of Clinical Child Psychology* 27:168-179., Individual articles on specific trials: Amerine-Dickens et al., 2006; Bushbacker et al., 2004; Dillenburger et al., 2004; Eikeseth et al., 2006; Eikeseth et al., 2007; Howard et al., 2005; Johnson & Hastings, 2002; Lovaas, 1987; McEachin et al., 1993; Ozonoff & Cathcart, 1998; Sheinkopf et al. 1998; Weiss & Delmolino, 2006; Sallows et al, 2005; Tonge et al., 2006.

¹² Personal research and experience of panel member L. Sikich, Aman MG, Langworthy KS, 2000. Pharmacotherapy for Hyperactivity in Children with autism and other pervasive developmental disorders. *Journal of Autism and Developmental Disorders* 30:451-459.

illness and often demand more intensive levels of care such as hospitalization.¹³ In the same trial, risperidone also resulted in significant reductions in core symptoms of repetitive behaviors.¹⁴ However, more and more rigorous and controlled trials of treatments (pharmacologic, dietary and behavioral) are being conducted and the evidence base is rapidly expanding.

In addition, the evidence to date suggests that early intervention may be especially usefully for individuals who are higher functioning with greater initial ability to demonstrate their intelligence and to use language,¹⁵ Generally, speech and behavioral treatments are used most often for younger children with autism, social skills therapies for children in the middle of the age range, and psychotropic medications, residential care, and hospitalization for adolescents and adults with autism.¹⁶

Evidence submitted by multiple insurers and/or their representatives clarified that they routinely exclude coverage of some treatments for autism, particularly those that involve behavioral treatments such as speech therapy and Applied Behavioral Analysis (ABA) therapy. The reason for excluding speech therapy or limiting the number of sessions seems to be that they do not believe that such therapies have a “reasonable expectation of achieving sustainable, measurable improvement in a reasonable and predictable period of time.”¹⁷ In addition, they note that some group customer benefits have blanket exclusions for autism.¹⁸ In a survey of 46 commercial, employment-based policies, Peele and colleagues found that all of the plans excluded autism.¹⁹ The insurers who responded did not provide data on the numbers of

¹³ Research Units on Pediatric Psychopharmacology Autism Network, 2002. Risperidone in children with autism and serious behavioral problems. *New England Journal of Medicine* 347: 314-321.

¹⁴ McDougle CJ, et al., 2005. Risperidone for the core symptom domains of autism: results from the study by the autism network of the research units on pediatric psychopharmacology. *American Journal of Psychiatry* 162: 1142-1148.

¹⁵ Lovaas, IO, 1987. Behavioral treatment and normal education and intellectual functioning in young autistic children. *Journal of Consulting and Clinical Psychology* 55: 3-9.; Sallows GO; Graupner TD, 2005. Intensive behavioral treatment for children with autism: four-year outcome and predictors. *American Journal of Mental Retardation*, 110:417-438.

¹⁶ Mandell DS, Morales KH, Marcus SC, Stahmer AC, Doshi J, Polsky DE, 2008. *Pediatrics* 121: e441-448.; Croen LA, Najjar DV, Ray GT, Lotspeich L, Serhal P, 2006. A comparison of health care utilization and costs of children with and without autism spectrum disorders in a large group-model health plan. *Pediatrics* 118: e1203-1221; Mandell,DS (2007). Psychiatric hospitalization among children with autism spectrum disorders. *Journal of Autism and Developmental Disorders*, Nov 2007, epub ahead of print; Aman MG, Lam KSL, Colliwe-Crespin A. (2003). Prevalence and patterns of psychoactive medicines among individuals with autism in the autism society of Ohio. *Journal of Autism and Developmental Disabilities* 33:527-534.; Ganz M (2007). The lifetime distribution of the incremental societal costs of autism. *Archives of Pediatrics and Adolescent Medicine*. 161:343-349.

¹⁷ Eg. Highmark letter 10-04-07, page 7, last item in 1st bulleted list.

¹⁸ Highmark letter 10-04-07, page 7 last full paragraph. Also see Highmark’s medical Policy on indications and limitations of coverage.

¹⁹ Peele PB, Lave JR, Kelleher KJ, 2002. Exclusions and limitations in children’s behavioral health care coverage. *Psychiatric Services*. 33:591-594.

participants they currently serve with autism spectrum disorders or the mean or median amount of care reimbursed.

The anecdotal statements from parents and some advocacy groups indicate that they are frequently denied health insurance coverage for affected children simply because of their diagnosis, that initial diagnostic evaluations are sometimes not covered when a final diagnosis of autism is made even though there was no diagnosis initially, that the treatments (especially allied therapies such as speech therapy) or recommended number of treatments are frequently not covered and that sometimes well child and routine pediatric care is not covered because a child has autism. No evidence was presented regarding the total number of denied claims.

Insurers contend that MA provides these services for all individuals with autism who need services in PA through PH-95.²⁰ However, it is clear from documentation provided by the DPW, Department of Insurance (DI), Speaker O'Brien, the Health Law Project, and anecdotal statements from concerned citizens that PH-95 does not provide complete coverage. Multiple factors create the incomplete coverage.

First, children must meet criteria for disability specified by MA. This almost always means they must first have a diagnosis (which would not be covered for many of the policies), and that they must be severely affected by autism so that they meet disability criteria. Yet, it is precisely those children who are less severely affected who may be most able to benefit from early intensive intervention and able to go on to adulthood with minimal sequelae of the illness.

Second, parents and advocates provide anecdotal evidence of frequent delays of several months before MA eligibility is approved. In the prevailing treatment model of autism delayed treatment is less effective treatment.

Third, the DPW, the DI, and concerned citizens and advocates raise concerns about limited numbers of providers who are willing to accept MA's reimbursement rate and various bureaucratic challenges involved with reimbursement. The citizens note anecdotally that this leads to frequent staff turnover, which can be extremely disruptive for a child with autism, and unqualified or poorly trained staff and very long waiting lists often with requirements to travel considerable distances for care. Also, it appears that MA benefits are frequently provided in the context of a managed care organization, which might refuse to provide high intensity services.

Fourth, DPW and parents raise concerns about frequent disruption of services associated with recertification of need multiple times per year. At least one parent reported that these re-evaluations were disruptive to her son's emotional well-being.

Fifth, DPW reports that 13,800 children with autism or about 60% of the expected number are served by the MA program. Several parents expressed discomfort with being on MA.

²⁰ Highmark letter 10-04-07, page 11; Independence Blue Cross letter 10-02-07, page 2; Blue Cross of Northeastern Pennsylvania letter 10-04-07, page 4; Capital Blue Cross letter 10-3-2007, p. 2.

The Panel's view based on the evidence submitted is that services are available to some Pennsylvania children with ASDs, but multiple barriers keep substantial numbers of children from receiving care that they need.

Extent to which the benefit would be utilized. No definitive evidence was provided in this regard. Three different research groups found that autism specific services are used by about 1/500 children (range 1/476 to 1/521).²¹ However, these numbers reflect the current widespread limitations in coverage, and therefore are likely to be underestimates of the extent of demand if coverage were provided. Johnson and Hastings²² found that financial limitations are a significant barrier to obtaining early intensive intervention. Some of these barriers (e.g., limited resources to cover transportation to appointments) might still be in effect even if the insurance mandate were in place. However, it seems likely that with one barrier (cost of service which is probably the most expensive) eliminated, use would increase.

Question 2. The extent to which coverage for the proposed benefit already exists, or if no such coverage exists, the extent to which this lack of coverage results in inadequate health care or financial hardship for the population of the Commonwealth.

Extent to which insurance coverage for the proposed benefit already exists

No scientific or comprehensive administrative data were made available to the review panel concerning (1) the number and proportion of insurers and policy-holders in the Commonwealth who currently have health insurance covering the mandated benefits proposed in HB 1150, (2) the range of services for individuals with ASD that are currently covered by Medical Assistance (Medicaid) and the current patterns of use of these services, and (3) how service use patterns for individuals with ASD under HB 1150 might vary from existing patterns of service use under Medical Assistance. As a consequence, the Review Panel found it difficult to state in precise quantifiable terms how much coverage exists for individuals with ASD, for which services, and whether the mandated benefits of HB 1150 are duplicative or complementary of existing coverage.

In a survey of benefit exclusions in 128 commercial, employment-based behavioral health plans managed behavioral health care plans, Peele and colleagues found that autism was excluded in 46 health plans that were in effect in 1996.²³ Insurance exclusions have led to efforts in various

²¹ Leslie DL, Martin A, (2007). Health care expenditures associated with autism spectrum disorders. Archives of Pediatrics and Adolescent Medicine 161:350-355.; Litak GS, Sutart T, Auinger P, (2006). Health care utilization and expenditures for children with autism: data from U.S. national samples. Journal of Autism and Developmental Disorders. 36:971-879; Mandell DS, Cao J, Ittenbach R, Pinto-Martin J (2006). Medicaid expenditures for children with autistic spectrum disorders: 1994-1999. Journal of Autism and Developmental Disorders 36: 475-485.

²² Johnson E, Hasting RP, 2002. Facilitating factors and barriers to the implementation of intensive home-based behavioral intervention for young children with autism. Child Care and Health Development. 28:123-129.

²³ Peele P, Lave J & Kelleher K. Exclusions and limitations in children's behavioral health care coverage. Psychiatric Services 53 2002: 591-94. These 46 plans were selected from 71 contracts with Magellan

states to achieve parity for autism and ASD relative to other childhood medical conditions. According to America's Health Insurance Plans,²⁴ thirteen states as of July 5, 2007 had mandated insurance coverage for autism or ASD disorders. In addition, coverage for the benefits mandated in HB 1150 is available in the Department of Defense Tri-Care²⁵ health insurance program for military dependents. Tri-Care is prohibited by federal law from covering special education or "unproven care," but it does cover "physician office visits, immunizations, and interventions such as speech therapy, physical therapy, and occupational therapy" for individuals with ASD. Tri-Care's Extended Care Health Option (ECHO) benefit allows cost-sharing of applied behavior analysis up to \$2,500/mo. or \$30,000/yr.

Other evidence submitted for review with regard to coverage consists of point-counterpoint commentaries by proponents and opponents of HB1150 about whether or not insurance coverage currently exists, the appropriateness of covering ASD services under health insurance policies, and the effects of cost-shifting from public (Medicaid) to private (group health insurance) payers.

Proponents of HB 1150 argue that Pennsylvania insurers have systematically excluded coverage for treatment and support services for individuals with an ASD. "Just as the infamous 'redlining' practices of the mortgage industry resulted in 'mortgage discrimination', the health insurance industry is inflicting 'diagnosis discrimination' by redlining individuals with autism diagnoses out from coverage."²⁶ Further, proponents maintain that ending insurance discrimination will increase access to medical care, treatment, and support services for children with autism while producing significant economic benefits to the families and other citizens of Pennsylvania that outweigh any costs associated with HB 1150. Among the benefits mandated by HB 1150 is Applied Behavioral Analysis (ABA). Proponents maintain that ABA is an effective means of ameliorating the varied symptoms of ASD; that private insurers exclude ABA treatments from most group policies; and that children in Pennsylvania have rarely had access to ABA through either public or private insurance systems.²⁷

Insurance companies and their representatives are among the major opponents of HB 1150 [Also see comments under Questions 3 and 8]. In essence, their position is that "a mandate is not justified where coverage is already available"²⁸ and that coverage for the mandated benefits under HB1150 already exists from the Department of Public Welfare through the PH-95 section

Behavioral Health because they were in effect for the entire 1996 calendar year, had stable enrollment, and enrolled at least 1,000 employees each.

²⁴ America's Health Insurance Plans: Summary of State Mandated Benefit Autism Laws—as of July 5, 2007. States are: CA, CN, GA, HA, IL, IN, KS, KY, LA, MO, NH, NY, SC.

²⁵ Department of Defense Report and Plan for Services to Military Dependent Children with Autism, 2007.

²⁶ Speaker of the House Dennis M. O'Brien, Rebuttal Statement in Support of the Cost-Effectiveness of HB 1150, November 19, 2007, p.1.

²⁷ Comments of James N. Boudier, The Vista Foundation, to Flossie Wolf, Pennsylvania Health Care Cost Containment Council, no date.

²⁸ Letter of John R. Doubman, The Insurance Federation of Pennsylvania, Inc., to Flossie Wolf, Pennsylvania Health Care Cost Containment Council, October 4, 2007, p. 2.

of Medical Assistance (Medicaid) which is available to Pennsylvania families without consideration of their income or insurance status.²⁹ Further, “(W)ith sufficient coverage available through a robust DPW program and provider network, we see no need to shift the cost of the current program – or any developmental disability program – to the private sector and further increase the cost of purchasing health insurance in Pennsylvania.”³⁰

Speaker O’Brien counters with the following rebuttal:³¹

- “HB 1150 simply requires insurance companies to pay a fair share of the cost of treating Pennsylvania children who have autism. It does not replace the current source of coverage that families receive through Pennsylvania’s Medical Assistance Program. The current program, known as Category PH-95, will continue to pay for treatments for families who do not have private coverage, and will continue as the payer of last resort for those who do have private insurance, covering, in many cases, co-pays and costs beyond the \$36,000 yearly limit.”
- “The PH-95 program has met many needs for families who have children with autism. However, this program is by no means guaranteed to continue into the future. In fact, at any time, the state or federal government could impose barriers to access such as participation premiums or income-eligibility requirements, adversely impacting families who are already paying premiums and co-pays for their private insurance.”
- “HB 1150 not only will result in a cost savings to the Commonwealth’s Medical Assistance Program, it also will result in a long-term cost savings to the health care and educational costs of the Commonwealth—accomplished through improved access to quality medical care, accurate diagnosis, access to treatment and intervention and support services. This benefit will extend far beyond the families who have loved ones with autism, and reaching all taxpayers.”

Based on the above considerations and related evidence it is clear that private health insurance companies in Pennsylvania currently exclude autism and ASD from group coverage. Autism services are covered through public insurance in the Medical Assistance (Medicaid) program administered by the Department of Public Welfare both in the regular program for Supplemental Security Income (SSI) beneficiaries and in Category PH95 for families whose incomes do not qualify for SSI participation. However, the Review Panel did not have access to a comprehensive description of current Medical Assistance service use by individuals with autism or ASD. Accordingly, we are not able to make a determination as to how much of the benefits

²⁹ Letter of Mary Ellen McMillan, Independence Blue Cross, to Flossie Wolf, Pennsylvania Health Care Cost Containment Council, dated October 2, 2007. See also: Letters of Floyd Warner, Pennsylvania Chamber of Business and Industry, August 8, 2007; Robert E. Baker, Capital Blue Cross, October 3, 2007; Michael Warfel, Highmark, Inc., October 4, 2007;

³⁰ Letter of Kimberley L. Kockler, Blue Cross of Northeastern Pennsylvania, to Flossie Wolf, Pennsylvania Health Care Cost Containment Council, dated October 4, 2007.

³¹ Cover letter of Speaker of the House Dennis M. O’Brien with Statement of Essential Background Information, to Flossie Wolf, Pennsylvania Health Care Cost Containment Council, October 4, 2007, p. 1-2. See also citation to Mr. O’Brien in footnote 26 above.

mandated by HB 1150 are currently covered by Medical Assistance. This data gap is especially notable with regard to the frequency, intensity, and duration of use of Applied Behavioral Analysis (ABA) under Medical Assistance. Most proponents identify access to ABA as one of the key benefit of HB 1150, but the Review Panel did not have adequate information to assess how much of the current need for ABA is met by Medical Assistance.

Extent to which lack of coverage results in inadequate health care or financial hardship

As above, no scientific data were presented to the Review Panel that quantified the scope and intensity of inadequate health care or financial hardship for parents of children with ASD in Pennsylvania that result from the lack of private health insurance coverage for the benefits mandated in HB 1150. The pertinent documentation submitted for review consists of statements of fact submitted by government officials, several published research reports that are based upon data collected in other states, and personal statements from parents and other relatives of children with ASD.

The Autism Task Force Final Report³² issued by the Department of Public Welfare in December 2004 contains extensive commentary on the inadequacies in the diagnosis, treatment, and support services for children in Pennsylvania with ASD and the impact of these inadequacies on families. The Task Force was comprised of over 250 family members of people living with autism, service providers, educators, administrators and researchers. It was charged with developing a plan for a new system of organization, financing, and delivery of services to people with autism in Pennsylvania. Among the inadequacies identified were limitations in the state mental health and mental retardation systems for identifying and treating autism and the shortage of qualified providers to diagnose and treat ASD due in part to low reimbursement rates and the lack of insurance coverage for some necessary services.

One published report that addresses the financial burden on families was included in the information submitted to the Council. Sharpe & Baker (2007) have reported in the Journal of Family and Economic Issues on a study of financial issues associated with having a child with autism.³³ Between July 2003 and May 2004, the authors surveyed a convenience sample of 333 parents and primary caregivers living in the Midwest who had a child with autism under age 19. They asked questions about autism-related expenses, receipt of publicly-funded services, financial problems, and employment difficulties. They analyzed responses to the following (yes/no) question: “During the past twelve months, has your family had financial problems because of your child’s autism or related conditions?” Two main characteristics distinguished the families who reported experiencing financial problems: (1) they utilized medical interventions and had unreimbursed out-of-pocket expenditures for medical doctor or therapy or for education expenses (by 121%, 264%, and 289%, respectively) and (2) those with incomes under \$40,000 were more likely to have financial problems than those with higher incomes. The authors also note that “Many survey respondents forfeited financial security and even experienced bankruptcy

³² Department of Public Welfare, Commonwealth of Pennsylvania, Pennsylvania Autism Task Force Final Report, Harrisburg, PA: Office of the Secretary, December 2004.

³³ Sharpe DL & Baker DL (2007). Financial issues associated with having a child with autism. Journal of Family and Economic Issues 28:247-264.

to provide needed therapy for a child with autism” (Sharpe & Baker, 2004, p. 247, 259). However, exact frequencies of these events were not reported.

Numerous testimonials from parents of children with ASD were also submitted to the Council. While not a representative sampling of all such parents in the Commonwealth, these letters nonetheless describe the social, psychological, and financial burdens that many families face in obtaining diagnostic, treatment, and support services for children with ASD. The following statements are excerpts from these letters:

- “Before my child’s diagnosis I was a tax-paying citizen, with a salary well above the mean, in a field—computer science—that was economically critical to Pittsburgh’s post-steel rebirth. I was, in other words, contributing to my family, my community, the state, and the country. Shortly after diagnosis, I had no choice but to walk away from that career in order to fight with our insurance company, navigate the morass of the Medicaid system, and, often, act as my child’s speech therapist, occupational therapist, play therapist, and educator when the system failed to provide for her. Of the hundred or so families I know with children on the spectrum, almost all of whom were two-career before diagnosis, only two still have full-time working parents. Lost wages, lost taxes, and lost potential are all costs that must be considered in any economic tally.”³⁴
- “I think I can best demonstrate the need for House Bill 1150 to become law by listing the “out of pocket” expenses I incurred over the last twelve years. My boy Christopher is fourteen and has autism. He is my best friend—my heart—my soul—I think I have paid out approximately \$600 thousand over the past 12 years.”³⁵
- “Because there is little or no insurance coverage for diagnostic team services, there are very few diagnostic teams. Even if a family has funds to pay for diagnosis, there is an extended wait for appointments. Appointments for new patients may be anywhere from 7 to 20 months away. My son has a follow-up appointment in Dec. 2007. This first-available appointment was scheduled in May!”³⁶
- “My son is unemployed and his wife is holding the family together financially. They have been through two rounds of speech therapy and one round of motor skills therapy, mostly at their own expense, and with whatever insurance coverage they could get. At this point they have exhausted all of their savings and used any insurance that might help him. Jack has improved and can now put 2 to 3 words together but he still can’t communicate. The therapy sessions have definitely helped

³⁴ Letter of Jill Fain Lehman, Pittsburgh, PA to Flossie Wolf, Pennsylvania Health Care Cost Containment Council, October 2, 2007.

³⁵ Letter of Bill Davis, Elizabethtown, PA to Flossie Wolf, Pennsylvania Health Care Cost Containment Council, October 1, 2007.

³⁶ Letter of Edwinna D. McHale, Palmyra, PA submitted to Pennsylvania Health Care Cost Containment Council, October 3, 2007.

but now because there is no more money or insurance coverage Jack's progress has really slowed down considerably."³⁷

- "While many in the insurance industry point to the fact that these children are being serviced through the State's Medical Assistance program, what they are NOT telling you is that the reimbursement rates for medical assistance are so incredibly low that very few providers accept MA. This, in turn, has created enormous waiting lists all over the Commonwealth who desperately need services...The average wait to receive speech therapy from a facility that takes medical assistance, if you can find one, is approximately 5 months. Imagine that someone you love has a horrible disorder that can be treated, but that treatment is being withheld for 5 months. How would you feel? What would you do? You would feel as we do – that precious time is ticking by along with a window of opportunity that can never be replaced."³⁸

Due to the absence of comprehensive utilization reports or other scientific data, the Review Panel was unable to determine the extent to which low Medical Assistance reimbursement rates limit timely receipt of services from the ASD provider network, whether there is an adequate number of ASD providers, and whether providers are adequately trained to provide the full range of ASD services, including Applied Behavioral Analysis (ABA).

Question 3. What is the demand for the proposed benefit from the public and the source and extent of opposition to mandating the benefit?

What is the demand for the proposed benefit from the public?

To gauge the demand for the proposed benefit from the public, one would need to assess the amount of unmet need and the amount of family out-of-pocket costs that would be covered by the mandate. The Panel reviewed evidence submitted on health care coverage, health care costs and expenditures, health services use, the burden of autism (financial and humanistic), and the economic evaluation (cost-benefit/cost-effectiveness) of autism treatments.

Because the size of the autism population is small relative to other chronic conditions affecting children and young adults, most administrative databases, insurance claims databases, and survey data contain too few individuals on which to draw solid policy conclusions and lack family out-of-pocket expenditures. Furthermore, because benefits for autism spectrum disorders (ASDs) are usually excluded from health insurance plans, insurance claims and administrative databases are not expected to include data on services for individuals with an ASD diagnosis. Analyses based on claims databases that do include those with ASDs may result in biased findings.

³⁷ Letter of Beverly Thompson, King of Prussia, PA to Flossie Wolf, Pennsylvania Health Care Cost Containment Council, September 20, 2007.

³⁸ Letter of Cindy L. Waeltermann, Wexford, PA to Flossie Wolf, Pennsylvania Health Care Cost Containment Council, September 29, 2007.

The submitted evidence, reviewed in detail below, does present evidence that children and young adults with ASD are expensive and that the increased costs of care, relative to children and young adults without ASD, are driven by direct medical costs (physician visits, psychotropic medications, psychiatric hospitalizations), direct non-medical costs (supported employment program), and indirect costs (lost productivity/income). However, as will be discussed below, the strength of this evidence varies and in some cases the submitted evidence is of insufficient quality to answer the question posed above.

Burden of Autism

A number of articles were submitted as evidence about the burden of autism. Järbrink, and Knapp (2001)³⁹ and Ganz (2007)⁴⁰ present data on the financial burdens of autism and Sánchez-Valle et al (2008)⁴¹ provide evidence about the humanistic burden of autism.

Järbrink and Knapp³⁹ present an often-cited cost of illness (COI) model from the UK perspective that is similar in methodological approach to the one published by Ganz (2007).⁴⁰ Costs for hospital services, other health and social services, living support, voluntary support, special education, medications, sheltered work (supported employment), day activities, lost productivity, family members' time costs, and family expenses were enumerated, costed, and combined to estimate the cost of autism. Informal care costs were excluded due to uncertainty and lack of information and direct costs did not include costs associated with unvalidated treatments or criminal justice. Although, in general, the cost model itself has face validity and is widely cited, this article, however, does not present strong evidence for the current United States context. This study uses data from many sources and the quality and validity of those underlying data are not clear. Although this study takes a societal perspective, it is not clear from this study if the costs are incremental or total costs.

More recently Ganz⁴⁰ estimated the lifetime costs of autism from a societal perspective for the United States. Using age- and sex-specific data on direct medical, direct non-medical, and indirect costs, Ganz estimated an average per capita discounted lifetime cost of \$3.2 million per person. This model is similar in construction to the model presented by Järbrink and Knapp.³⁹ Ganz, however, provides the costs of each component of care in 5-year age categories which allows the reader to understand which costs are more relevant at different ages. The relative importance of different costs at different ages provides information on the source of payments. According to Ganz, the total discounted lifetime costs of behavioral therapies (ending at age 21) are \$206,333 which is the largest component of direct medical costs. These behavioral therapies were estimated to cost more than the total lifetime costs of special education per child (\$150,483). Although this article has been cited numerous times in the package of evidence submitted to the

³⁹ Järbrink K, Knapp M. The economic impact of autism in Britain. *Autism*. 2001;5:7-22.

⁴⁰ Ganz ML. The lifetime distribution of the incremental societal costs of autism. *Archives of Pediatrics and Adolescent Medicine*. 2007;161:343-349.

⁴¹ Sánchez-Valle E, Posada M, Villaverde-Hueso A, et al. Estimating the burden of disease for autism spectrum disorders in Spain in 2003. *Journal of Autism and Developmental Disorders*. 2008;38:288-296.

Panel and although it has been cited by a number of state governments to support extended services and mandated health insurance expansions for children and adults with autism (Missouri Department of Mental Health, the Alaska Governor's Council on Disabilities and Special Education, Caring for Washington Individuals with Autism Task Force, Arizona Autism Insurance Council, and the Nevada Department of Health and Human Services Autism Summit report), it still suffers from some of the same criticisms as the Järbrink and Knapp, namely that it relies on a number of simplifying assumptions and uses data from many sources and the quality and validity of those underlying data are not clear.

In addition to economic burden of autism, there is a considerable humanistic burden of autism. Sánchez-Valle, et al⁴¹ present an estimate of the disability adjusted life years (DALY), which is a population-level measure of the burden of illness. Using data from Australia on autism incidence rates and standardized mortality rate data from California to compute the DALYs associated with autism, Sánchez-Valle et al estimate that autism is responsible for 44,000 DALYs lost in Spain. These results imply that early diagnosis and treatment may be able to reduce DALYs lost.

Exclusions, Limitations, and Access to Care

Peele et al⁴² analyzed data from 128 behavioral health plans that were in effect in 1996 and 1998 to determine the exclusions and limitation in coverage. They found that a significant proportion of plans had benefit exclusions and limitations for ASDs. The authors concluded that affordability of treatment (health plan coverage increases affordability for families) is an important determinant of access. Exclusions and high copayments were also important determinants of access. Because of benefit limitations, the authors report that parity legislation did not often meet the health care requirements of children with behavioral health needs. Furthermore if children exceeded their yearly benefit they would be, in effect, uninsured for the rest of the year. Although this article does present evidence that ASD-related exclusions and limitations reduce access to care, and therefore provides evidence that there is an unmet need for services that the mandate would address, this study uses old data on health plans that were not selected in a random or systematic way.

Health Care Utilization, Expenditures, and Levels of Unmet Need

Croen et al⁴³ examined data from the Northern California Kaiser-Permanente (KP) database. The data in the KP system is approximately representative of the population residing in KP's catchment area, but because of the characteristics of those enrolled in KP, the lower and upper income groups are underrepresented in this database. Differences in income, all else the same, are unlikely to introduce bias since there are no known differences in autism incidence rates by income level. However, lower income groups are more likely to be enrolled in Medicaid

⁴² Peele PB, Lave JR, Kelleher KJ. Exclusions and limitations in children's behavioral health care coverage. *Psychiatric Services*. 2002;53:591-594.

⁴³ Croen LA, Najjar DV, Ray GT, Lotspeich L, Bernal P. A comparison of health care utilization and costs of children with and without autism spectrum disorders in a large group-model health plan. *Pediatrics*. 2006;118:e1203-e1211.

and hence, family and child characteristics associated with Medicaid enrollment are likely to be underrepresented in the KP data. This study featured a large sample size and the analyses adjusted for a selected set of patient characteristics. This study does provide evidence that children with ASD diagnoses utilize health care services more intensely than children without ASD diagnoses and are responsible for higher health care costs. Total costs for children with ASD diagnoses are about three times larger than children without ASD diagnoses, which is consistent with previous literature. Prescription medication and hospitalizations are important contributors to the cost differential. Although unlikely to introduce substantial bias, this study, however, may have utilized a suboptimal statistical technique to compute costs adjusted for child characteristics (ordinary least squares (OLS) regression using raw dollars as the outcome variable rather than a regression model using log-transformed cost data or another regression technique such as the generalized linear model). Hospitalizations (psychiatric and non-psychiatric), outpatient visits, and psychotherapeutic medications were the main cost drivers. Children with ASDs and comorbid psychiatric conditions cost substantially more than children without ASDs (but with comorbid psychiatric conditions) indicating that the presence of behavioral and social impairments complicate the management of children with ASDs. The authors speculate that in the absence of evidence-based biomedical therapies for the core symptoms of ASDs that providers prescribe psychotherapeutic agents to target the psychiatric comorbidities. Although this is a well designed study that includes a non-ASD control group, to the extent that certain ASD-related services are already included in KP's benefit package, this article does not provide evidence in that there is an unmet need for services that the mandate would address. However, these costs may be underestimates because services that are not paid by the KP plan were not included. The article does not discuss whether EIBI services were included or excluded.

Following the work of Croen et al., Leslie and Martin⁴⁴ estimated the costs associated with autism in traditional health care settings using a national health insurance claims database (Thompson's MarketScan). This database includes data on 4.5 million covered lives from employer-sponsored private health plans and includes data on physician visits, hospitalizations, and pharmacy claims. Using data on 9,506 patients with an ASD from 2000-2004, the authors estimated that total costs for patients with an ASD ranged from \$5,316 per patient in 2000 (\$47,379 per 10,000 patients) to \$6,706 in 2004 (\$114,710 per 10,000 patients) [all amounts in 2004 dollars]. These costs are underestimates because not all plans cover ASD and services delivered in non-traditional settings (for example, in schools or residential treatment) are not captured. Out-of-pocket costs are also not captured (they are usually not captured in these types of studies). The authors note that these costs are low relative to other mental health diagnoses (bipolar disorder, mental retardation, and psychosis). This study provides additional data that children with ASDs are expensive (although this study does not provide the costs of children without ASDs or other mental health disorders for comparison purposes). It does not present cost data by category of cost (outpatient, inpatient, medications, for example), so it is difficult to compare these results to other studies that do. This study is also limited by the fact that these results are from patients covered under private insurance schemes, many of which are self-insurance plans sponsored by employers and are excluded from the mandate under consideration.

⁴⁴ Leslie DL, Martin A. Health care expenditures associated with autism spectrum disorders. *Archives of Pediatrics and Adolescent Medicine*. 2007;161:350-355.

The studies by Croen et al and Leslie et al used managed care/private insurance data to estimate the costs of ASDs. Because the care for a large proportion of children with an ASD is financed by Medicaid, those studies provide incomplete data. Mandel et al⁴⁵ used 2001 Medicaid data on children from all 50 states plus the District of Columbia to investigate psychotropic medication use. The authors identified 60,641 children with ASDs and utilized random effects regression models used to account for clustering of children by state and county. They found that 56% of children used at least one prescription medication and among those who used medication, 20% were using 3 medications concurrently. Neuroleptics (31%) were the most common, followed by anti-depressants (25%), stimulants (22%), mood stabilizers (21%), anxiolytics (12%), and sedatives (3%). Older children were more likely to have used medication (18% of children 2 and under used medications and 32% of children 3-5 used medications) and 61% of children with Asperger disorder used psychotropic medications versus 53% of children with autistic disorders. This study used a good quality design with a large representative database and many of the patterns reported in this study are as expected and are similar to previous work. However, the use of ASD diagnosis codes in Medicaid claims have not been validated, although previous chart reviews indicated >97% positive predictive value of such diagnosis codes recorded in encounter data. A limited set of clinical (including severity level) and county-level characteristics that are correlated with medication use are available for these analyses.

Mandel and colleagues also used Medicaid data to investigate overall health care expenditures for children with autism.⁴⁶ Using Medicaid claims data on children 21 and younger for services delivered in 1994-1999 in Allegheny County, PA, Mandell et al reported that children with an ASD diagnosis (N=334) had health care services that had reimbursed expenditures (about \$10,000 per year in 1999 dollars) that were 9 times higher than other Medicaid-eligible children (N=183,488) and 3.5 times higher than children diagnosed with different developmental delays (N=1,467). Inpatient psychiatric care and outpatient psychiatric services accounted for major portion of the difference in costs. This study did not capture all of the autism-related services that the children receive (e.g., the authors note that the Department of Education is responsible for considerable portion of the expenses). Although this study was limited to Allegheny County, it does provide evidence that, at least from 1994-1999, children with autism were responsible for considerable psychiatric costs. This study does not present estimates of family out-of-pocket expenses that the PA Medicaid program did not cover, nor was there a discussion the types of services that the Medicaid program did not cover, so it is difficult to draw conclusions about the level of unmet need and demand for the proposed mandate from this study.

In addition to proprietary insurance claims data and Medicaid claims, national survey data can also be used to investigate the utilization and expenditure patterns (and hence unmet need) of individuals with ASDs. Liptak et al⁴⁷ used data from 3 sources, the Medical Expenditure

⁴⁵ Mandell DS, Morales KH, Marcus SC, Stahmer AC, Doshi J, Polsky DE. Psychotropic medication use among Medicaid-enrolled children with autism spectrum disorders. *Pediatrics*. 2008;121:e441-e448.

⁴⁶ Mandell DS, Cao J, Ittenbach R, Pinto-Matrin J. Medicaid expenditures for children with autism spectrum disorders: 1994 to 1999. *Journal of Autism and Developmental Disorders*. 2006;36:475-485.

⁴⁷ Liptak GS, Stuart T, Auinger P. Health care utilization and expenditures for children with autism: Data from U.S. national samples. *Journal of Autism and Developmental Disorders*. 2006;36:871-879.

Panel Survey (MEPS), the National Ambulatory Medical Care Survey (NAMCS), and the National Hospital Ambulatory Medicare Care Survey (NHAMCS) for various years from 1997 to 2000. The authors compared children with ASDs to children with depression, mental retardation, and “children in general.” Children with ASDs were less likely to have received psychotherapy. Costs for children with an ASD were higher than the other groups (\$6,132 vs. \$5,851, \$1,626, \$860). Drivers of these differences include outpatient visits (number of visits twice that of children with depression, 42 vs. 20, and almost 9 times that of children with MR), physician visits, and prescription medications (risperidone and clonidine were the most common). Family out-of-pocket expenses for children with an ASD were \$613 and were \$687, \$161, and \$193 for children with depression, mental retardation, and for children in general, respectively. Although this study used nationally representative survey data and therefore contributes to this literature by rounding out the sources of cost data, aspects of this study’s quality limits its value as evidence that there is an unmet need for services that the mandate: the base year for costs is not reported; children in institutional settings are not included (a common drawback in all of the studies reviewed here); diagnosis codes (in the case of the MEPS) were self-reported by the parents and the MEPS does not report all 5 digits of the diagnosis code so true ASD could not be uniquely identified. A major limitation is the small sample size of this study: 31 cases were identified in the MEPS and 80 from the NAMCS/NHAMCS, which means that the confidence intervals around estimates is likely to be wide. The Agency for Healthcare Research and Quality (the administrator of the MEPS) warns against analyses based on fewer than 100 cases.

Utilization and Expenditures on Other Autism-Related Services and Needs

Because existing surveys do not address the data needs of the autism health services research community, Järbrink, Frombonne, and Knapp⁴⁸ discussed the development of a data collection tool (questionnaire) to obtain data on the cost and time to support children with autism. Responses to this questionnaire were combined with unit cost data to compute the incremental costs of autism. In this pilot study data on 15 of 16 children were analyzed. Parents estimated that they lost about 22 hours of work per week due to their child’s autism. Out of pocket costs were assessed by the questionnaire and by a diary (the diary yielded higher costs). Although this study presents a method that can be used in future studies of the costs associated with autism, especially family out-of-pocket costs, the data from this particular study are limited by its very small sample size.

It is possible for young adults with high-functioning autism to be employed with the proper supports. Because supporting employment for individuals with autism does involve extra training and the involvement of support staff, there are associated costs. Järbrink et al⁴⁹ examine the cost implications of young adults with high functioning autism. Using data from a study conducted from 2000 to 2003 in 4 communities in Sweden the Järbrink et al examined the types of and amounts of services used by people with ASD looking for employment. Baseline interviews were conducted with 19 individuals (relatively high functioning and many had received some education). Health care comprised about 25% of the total costs associated with the

⁴⁸ Järbrink, Frombonne, and Knapp, 2003

⁴⁹ Järbrink K. The economic consequences of autistic spectrum disorders among children in a Swedish community. *Autism*. 2007;11:453-463.

care of these individuals. Almost 70% are productivity losses and community support-related costs. Individuals were followed-up about 10-18 months later. Total costs decreased by 86% (66% of the decrease was from decreased outpatient costs that resulted from the use of mobile teams that visited the individuals with ASD). Because supported employment benefits are not the target services of the proposed mandate, it is not clear how this study provides evidence on the demand for the proposed benefit. This study relied on many assumptions, was purely descriptive (no statistical tests were performed), did not utilize a control group, used a small sample size (implications for power), and used a regional Swedish sample.

The cost and utilization studies reviewed to date have relied on large preexisting databases and have provided evidence, regardless of its quality, that children with ASDs cost more to care for than children without ASDs and that outpatient care, hospitalization, and psychotropic medications drive those higher costs. The extent of unmet need for services that the mandate would cover is not necessarily clear from those studies, but there is evidence of substantial family out-of-pocket costs and of the use of medications and psychiatric hospitalization that may be used to manage complex cases. Mandell,⁵⁰ instead designed a survey to estimate the prevalence and risk factors associated with psychiatric hospitalization among children with ASD. The authors fielded a survey that recruited, by postal mail, 273 caregivers of children with ASD who previously expressed interest in participating in a survey. Researchers contacted 173 autism care provider organizations, requesting that they distribute letters to families. The survey was developed through 7 focus groups with parents of children with ASD. Data were collected on 760 children ages 5-11 with diagnoses of ASD and Asperger condition, and PDD-NOS (out of 1,027 returned surveys, 760 were usable). The characteristics of the children in the survey were comparable to 5,200 children ages 5-21 in PA that were receiving autism-related services through special education in 2003. Mandell found that the lack of appropriate community services available for children with ASD and their aggressive and self-injurious behaviors may be a risk factor for hospitalization. The authors found that the measures representing unmarried/not cohabiting parents, self-injurious behaviors, aggression toward others, depression, OCD, and ever use of a psychotropic medication were all positively related to sooner time to a psychiatric hospital admission. These findings imply that family resources are important and that behavioral interventions that target aggression and self-injurious behaviors have help prevent or reduce psychiatric hospitalizations. This study is limited by the fact that the validity of self-reported ASD in a mail survey has not been established, the survey did not ask about all symptoms, and it was not a random sample.

Economic Evaluation of Expanding Autism-Related Services

The studies reviewed above present both the economic and humanistic burden of autism. To argue that expanded coverage for autism services as the mandate addresses will have economic benefits aside from any benefits in terms of equity and access to care, requires an economic evaluation that compares the costs of autism-related services to the immediate and longer-term economic and non-economic outcomes. In a series of studies presented below, Jacobson, Mulick, Järbrink, Frombonne, Knapp, and Chasson review the results of economic

⁵⁰ Mandell DS. Psychiatric hospitalization among children with autism spectrum disorders. *Journal of autism and Developmental Disorders*. (In Press; Online November 2, 2007).

evaluations to support the cost-effectiveness of early intensive behavioral interventions (EIBI). These articles are somewhat dated, rely on small samples and numerous and sometimes untested assumptions, and have been critiqued in the literature.

One of the most cited articles to support the economic value of EIBI is the study by Jacobson et al (1998)⁵¹ that presented a cost-benefit analysis of EIBI based on old treatment patterns and sets of assumptions about the effectiveness of EIBI. Their model predicted cost savings (in 1998 dollars) resulting from EIBI ranging from \$187,000 to \$203,000 per child 3-22 and \$656,000 to \$1,082,000 per child for ages 2-55, depending on assumptions about effectiveness. The cost savings are driven by reductions in special services such as special education and adult services. This model is not based on data from actual recipients of EIBI, but rather it is based on numerous assumptions about effectiveness and the associated reductions in the need for specialized services as a result of EIBI and hence it is difficult to judge the evidentiary value of this study. Marcus et al⁵² critiqued Jacobson et al.'s cost-benefit analysis noting that their use of income as a measure of long-term benefit was questionable and that their assumptions about the effectiveness of EIBI were unsubstantiated by any evidence and lacked a theoretical foundation.

In a follow-up review article, Jacobson and Mulick,⁵³ presented a critique of the cost-benefit literature for not accounting for value (health-related quality of life) in evaluating health interventions. The authors argue that intensive behavioral interventions place financial burdens on young families. Early intensive behavioral interventions (EIBI), a method of applied behavioral analysis (ABA), could be beneficial for children with PDD. The authors claim that EIBI (at a level of at least partial benefit) would result in a net benefit of at least 1 million dollars. In the case of the EIBI resulting in little or no benefit, the EIBI would result in costs of 4.4 million. This article provides anecdotal evidence of insufficient quality for policy purposes. However, this article does not provide enough evidence to evaluate different delivery models or therapeutic approaches. Marcus et al⁵² comment that Jacobson et al⁵¹ try to demonstrate that the benefits outweigh the costs of EIBI “because they *assume* [sic] EIBI is the most effective treatment.”

In a more recent cost-benefit analysis of EIBI, Chasson, Harris, and Neely⁵⁴ compared the costs and outcomes of EIBI and special education for children with autism in Texas. They used a simplified version of Jacobson et al's (1998)⁵¹ method and used a dichotomous outcome indicator to capture the treatment effectiveness of EIBI. Similar to Jacobson et al., the authors made assumptions about the proportion of children that improved and could be mainstreamed due

⁵¹ Jacobson JW, Mulick JA, Green G. Cost-benefit estimates for early intensive behavioral intervention for young children with autism: General model and single state case. *Behavioral Interventions*. 1998;13:201-226.

⁵² Marcus LM, Rubin JS, Rubin MA. Benefit-cost analysis and autism services: A response to Jacobson and Mulick. *Journal of Autism and Developmental Disorders*. 2000;30:595-598.

⁵³ Jacobson JW, Mulick JA. System and cost research issues in treatment for people with autistic disorders. *Journal of Autism and Developmental Disorders*. 2000;30:585-593.

⁵⁴ Chasson GS, Harris GE, Neely WJ. Cost comparison of early intensive behavioral intervention and special education for children with autism. *Journal of Child and Family Studies*. 2007;16:401-413.

to EIBI, although the authors recognized that there is no way to predict the outcome (the authors did cite a relatively recent article⁵⁵ that replicated results from the original Lovaas article⁵⁶). The authors assumed that after 3 years of EIBI, there would be a 72% offset in special education costs over 15 years, resulting in a savings of \$84,300 per child; including actual costs (state plus family expenditures) results in a savings of \$208,505 per child. This study suffers from many of the same limitations as the earlier Jacobson et al. article⁵¹ including not discounting future costs (as is the convention) and failing to perform any sensitivity analyses. Although the authors tried to address the criticism that the Jacobson et al. paper relied on outcomes data from the Lovaas article,⁵⁶ the results of which were not replicated, by citing a Sallows and Graupner,⁵⁵ it should be noted that Sallows and Graupner study, which reported the evidence in favor of a beneficial effects of the EIBI, did not employ a control group (“twenty-four children with autism were randomly assigned to a clinic-directed group, replicating the parameters of the early intensive behavioral treatment developed at UCLA, or to a parent-directed group that received intensive hours but less supervision by equally well-trained supervisors”) and did not find that the EIBI did better than the parent-directed group; they did find that after 4 years of treatment 48% of all children showed rapid learning and at age 7 were succeeding in regular education classrooms.

Recently Motiwala et al performed a cost-effectiveness analysis⁵⁷ from the perspective of the government of Ontario, Canada. The authors compared 3 alternatives: the status quo (37% of children ages 2-5 received up to 3 years of IBI for 23 hours per week), expansion of IBI services to all children, or no intervention (0% of children received province-funded IBI services). In this study, the effectiveness rates for expansion and no intervention were based on the literature (and were on conservative) and the effectiveness rates for the status quo were based on current data (36.9% of children will have normal functioning, 34.3% will be semi-dependent, and 38.9% of children will be very dependent). Costs came from Ontario government sources. Depending on the level of dependency resulting from the IBI therapy, the number of dependency-free years gained to age 65 was calculated. Dependency included special education, adult day programs, disability supports, and assisted employment. The expansion strategy was the dominant one, yielding more incremental discounted dependency-free years gained (4.6 compared to no intervention and 2.8 compared to the status quo) and the highest discounted savings (\$53,720 compared to no intervention and \$34,479 compared to the status quo). In sensitivity analyses, the authors varied the effectiveness of EIBI to account for the uncertainty and controversy in the literature. The sensitivity analyses suggested that a significantly lower level of treatment effectiveness than the base case would be needed to change the conclusion that expanding EIBI coverage to all children with autism in Ontario was the dominant strategy (i.e., largest incremental savings and largest incremental benefit in terms of dependency-free years). This study provides good evidence of the cost-effectiveness of expanding IBI to cover all children within a defined administrative area (Ontario, Canada). This study relies on more defensible and

⁵⁵ Sallows GO, Graupner TD. Intensive behavioral treatment for children with autism: Four-year outcome and predictors. *American Journal of Mental Retardation*. 2005;110:417-438.

⁵⁶ Lovaas OI. Behavioral treatment and normal educational and intellectual functioning in young autistic children. *Journal of Consulting Psychology*. 1987;55:3-9.

⁵⁷ Motiwala SS, Gupta S, Lilly MB, Ungar WJ, Coyte PC. The cost-effectiveness of expanding intensive behavioural intervention to all autistic children in Ontario. *Healthcare Policy*. 2006;1:135-151.

transparent assumptions than previous economic evaluations of EIBI, utilizes real-world data where appropriate and available, and presents a set of sensitivity analyses to allow readers to assess the quality of their results.

Overall Assessment

Overall the evidence presented to the Panel to evaluate does tell a consistent story that children with ASD diagnoses demand and use more services than children without ASD diagnoses, and therefore cost more to care for and support than children without ASD diagnoses. However, in some cases there are few data available to make an argument in favor or against the mandate. The data on the increased costs of children with ASD diagnoses vary in quality. For example the articles by Järbrink and Knapp³⁹ and Ganz⁴⁰ rely heavily on assumptions and data from various sources and of varying quality and the article by Liptak et al⁴⁷ rely on very small samples from national surveys, one of which does not allow researchers to precisely identify ASDs using diagnosis codes. On the other hand, articles by Croen et al,⁴³ Leslie and Martin,⁴⁴ and Mandel et al⁴⁵ all applied rather strong research designs to high quality data. Articles on the economic evaluation (the assessment of the value) of EIBI also varied greatly in terms of quality. The work by Jacobson, Mulick, and Green^{51,53} has been widely criticized in the literature. On the other hand, the cost-effectiveness study by Motiwala et al⁵⁷ meets professional research standards by presenting defensible and transparent assumptions and uses real-world data where appropriate.

What is the extent of opposition to mandating the benefit?

The evaluation of the evidence opposing the mandate has been discussed sufficiently elsewhere in this report (see Question 8).

Question 4. All relevant findings bearing on the social impact of the lack of the proposed benefit.

Extensive information is included in the submitted evidence regarding the social impact of the lack of the proposed benefit (references provided in the detailed discussion that follows). There is considerable evidence of short term social impacts affecting the families of children with autism, schools, tax base and the Pennsylvania Medicaid program. Lack of the benefit clearly leads to delays in diagnosis and in implementing recommended treatments. Such delays are likely to directly impact families and educators of affected children. In addition they are likely to indirectly effect public schools and the Pennsylvania Medicaid system as they are required to provide specialized education and more intense psychiatric treatment to children who have more severe autism-related impairments because they failed to receive early intervention. The resources expended by these public agencies to meet the needs of children with autism who do not receive the benefit will either be taken from other programs in the agencies that serve other Pennsylvanians or will need additional tax support.

Lack of the benefit also results in unreimbursed medical expenses for many families who feel compelled to provide whatever treatment they can and but are not accessing those services through Medicaid. Several citizens and one survey reported that it is frequent for one parent to

withdraw from the work force in order to provide such services directly or advocate for them. Loss of these parents from the work force reduces the tax base and may increase the likelihood of family bankruptcy. In the case of single parent families the requirement for intense parent involvement to the exclusion of paid work may lead to need for welfare assistance. Utilizing all one's savings, retirement and college funds also increases the likelihood of financial catastrophe and dependence on welfare agencies for both the parents and for the affected child with autism once s/he becomes an adult.

Finally, lack of the benefit and failure to provide sufficiently intense treatment (ABA) through Medicaid appears to reduce the number of individuals with autism who are able to achieve higher levels of functioning. Put another way, lack of the benefit and associated failure to provide sufficiently intense treatment is likely to increase the number of individuals who are dependent upon others for housing, supervision and vocational support as adults. Such services must be provided by the state, which will require funds be taken from other programs or increased taxes. It also seems likely that the healthcare needs of more severely ill youth and adults with autism will be greater than the healthcare needs of youth and adults with milder symptoms. Most often state assistance programs will pay for the needed healthcare of these disabled individuals.

Detailed discussion of each of these social impacts follows.

Diagnostic and treatment delays as well as inadequate treatment resulting in more severe illness clearly increase stress on parents. One study found that the mean depression score among parents of children with autism was twice that found in community surveys and that 45% of the sample (68 parents) met the cut off for a major depression.⁵⁸ Parental depression is well established to adversely affect the mental health and development of typically developing children who may be siblings of the autistic child. Further more severe autistic symptomatology is linked to higher levels of depression and stress, which – in contrast to moderate or mild symptomatology – was not sensitive to support provided by others in the community. Several studies (initial reports not provided) have noted that autism seems to affect the family (parents and siblings) to a greater extent than other developmental disorders.⁵⁹ Several of the letters from citizens also cited a divorce rate of 80% among parents of children with autism, although no scientific evidence supporting this was presented. If the rate is indeed that high, there is social impact on higher costs of monitoring child support payments and greater likelihood that children will live in poverty if living in single parent families. Further, the rate of psychiatric

⁵⁸ Benson, PR (2006). The impact of child symptom severity on depressed mood among parents of children with ASD: the mediating role of stress proliferation. *Journal of Autism and Developmental Disabilities*. 36:685-695.

⁵⁹ Bouma; R & Schweitzer, R.; 1990. the impact of chronic childhood illness on family stress: a comparison between autism and cystic fibrosis. *Journal of Clinical Psychology* 46:722-730.; Moes,D.; 1995. Parent education and parent stress. In RL Koegel & LK Koegel (Eds.) *Teaching children with autism* (pp.79-94) Baltimore: PH Brookes Publishing.; Rodrigue,JR; Morgan,SB; Geffken,; 1990. Families of autistic children: psychosocial functioning of mothers. *Journal of Clinical Child Psychology* 19: 371-379.

hospitalization for children with autism in single parent families was greatly increased (odds ratio 2.54).⁶⁰

Several letters from concerned citizens describe the impact of such diagnostic and treatment delays upon the families of autistic individuals. Ami Amada notes “The emotional stress level of all of this has taken a toll with me and I experienced a mental breakdown last year needing my own medication, loss of work time, and marital stresses. My husband’s blood pressure and stress levels are at an all time high . . . therapies also include help for our 5 year old [typically developing] daughter.” The Moses family states “Words cannot describe the emotional agony involved knowing that your child has autism, but cannot obtain immediate treatment because your health insurance carrier will not cover the services . . . Working families going through the emotional trauma of an autism diagnosis are further injured when we apply for government benefits . . . and [are] treated as if we are asking for handouts.”

Clinical consensus and multiple treatment guidelines and studies clearly indicate that treatment is most effective when started as early as possible. Studies have found that children who begin treatment after age 4-5 years, generally show significantly fewer benefits than children who begin treatment prior to that age. Penske et al (1984) as cited in Rogers (1998) found that 6 of 9 children who began treatment prior to age 5 were able to attend public schools with 4 of these in regular classes whereas only 1 of 9 children who began treatment after age 5 was able to function in a public school even after 6 years of intensive treatment. Further, Lovaas (1987) and Sheinkopf and Siegel 1995 found that young children (less than 3yrs) receiving ABA showed approximately a 25-30 point increase in IQ whereas those who began a similar treatment at age 4-7 (Eikeseth et al, 2002) showed only a 17 point mean increase in IQ. (However, there was also a difference in duration of treatment between the two studies that may also have contributed to differences.) There is evidence that links improvements in IQ both to increased ability to function in regular education, and to reduced problem behaviors that are no longer in the clinically significant range (Sallows and Gaupner 2005). This suggests that delays in diagnosis and implementation of recommended treatments will increase the need for prolonged specialized education interventions costing the public school systems approximately \$12,935 /student to provide compared to regular education which is estimated to cost \$7543/ student.⁶¹ Such increased expenses for school districts necessarily require cuts in programs for children without special needs or increased tax support. Further, there are concerns about the supply of trained teachers for such children. In addition, Howlin and colleagues (2004) found that IQ > 70 seemed to be the threshold for being able to engage in some work and to live somewhat independently in adulthood. The ability to be primarily educated in mainstream schools also was related to vocational success and independence.⁶²

⁶⁰ Mandell, DS (2007). Psychiatric hospitalization among children with autism spectrum disorders. *Journal of Autism and Developmental Disorders*, Nov 2007, epub ahead of print.

⁶¹ Jacobson, JW; Mulick JA; Green G, ;1998. Cost-Benefit estimates for early intensive behavioral intervention for young children with autism—general model and single state case. *Behavioral Interventions* 13:201-226.

⁶² Howlin P, Goode S, Hutton J, Rutter M, (2004). Adult outcome for children with autism. *Journal of Child Psychology and Psychiatry*, 45:212-229.

In addition, children with more profound symptoms are more likely to require ongoing psychiatric care and psychotropic medications which are also extremely expensive. A survey of more than 1000 Pennsylvania families with children with autism found that diagnosis of milder forms of illness reduced the risk of hospitalization by more than 50% and that later age of diagnosis modestly increased the rate of hospitalization.⁶³ Further, the length of psychiatric hospitalizations for children with autism (mean 25 days, median 14 days, mean cost \$6714) is significantly greater than for children with mental retardation (mean 13 days, median 6 days, mean cost \$1405) or other psychiatric disorders (mean 5 days, median 1 day, mean cost \$322).⁶⁴ Studies of other insurance and medical service use databases confirm higher costs per affected person (eg. total health care cost in autism of \$6132, in depression of \$5851, in mental retardation of \$1626 and in children without these disorders of \$860 with the same, but more pronounced pattern in the prescription medication costs/person (eg. autism-\$971, depression-\$642, mental retardation-\$615, and other-\$77).⁶⁵ The PA Medicaid system currently absorbs many of these costs through the PH95 program in the absence of the benefit. “The Pennsylvania Commonwealth Insurance Department Actuaries estimate, based on data from DPW, that the MA program could realize a saving of \$15.3 million in the first year if the mandate were passed and in effect for only 9 mths.⁶⁶ Using a slightly different method for calculating the number of self-insured plans that would be exempt, The DPW Bureau of Budget MA Section estimated that \$16.5 million⁶⁷ to \$22.2 million⁶⁸ would be saved in the first year (2008-2009). Similar savings would also be incurred by the Federal government because they contribute 54% of MA costs. Without the mandate, the state government will probably continue to spend \$22.2 million per year providing care to children with ASDs. These expenditures will decrease resources available to address healthcare needs of other poor Pennsylvanians and/or lead to increased taxes

Numerous letters from concerned citizens speak about the unreimbursed treatments they have paid out of pocket. Although the costs reported are in the thousands of dollars, they seldom exceed the proposed cap of \$36,000. Several citizens also describe the time and emotional energy they spent appealing to their insurance company to secure the services their children

⁶³ Mandell, DS (2007). Psychiatric hospitalization among children with autism spectrum disorders. *Journal of Autism and Developmental Disorders*, Nov 2007, epub ahead of print.

⁶⁴ Mandell DS, Cao J, Ittenbach R, Pinto-Martin J (2006). Medicaid expenditures for children with autistic spectrum disorders: 1994 to 1999. *Journal of Autism and Developmental Disorders*, 36:475-485.

⁶⁵ Liptak GS, Stuart T, Auinger P, (2006). Health care utilization and expenditures for children with autism: data from US national samples. *Journal of Autism and Developmental Disorders*, 36:871-879.

⁶⁶ March 6, 2008 letter to Mr. Volavka from The Commissioner of the Pennsylvania Insurance Department, Joel Ario, page 6 and Table 1, page 9..

⁶⁷ Cited in Joel Ario 3-6-08 letter footnote 24, page 6

⁶⁸ DPW document Estimated Fiscal Impact of HB 1150, revised July 6, 2007. estimates 7000 children with ASDs have private insurance and that the costs for these children to MA would be reduced by 50% to compensate for insured children who would not be subject to the mandate. Further, the state only pays 46% of the MA costs with the federal government paying 54%. The calculation is as follows \$14900 (annual cost of care for ASD child) x 0.921 (proportion for medical not educational care) x 7000 children with private insurance x 0.5 (to account for 50% with insurance not subject to the mandate) x 0.46 (state's share of MA expenses) = \$22,093,869.

needed. Researchers estimate that parents with a child with autism typically spend 40hrs/wk in direct care of child with autism 22 hrs of which would have been paid work.⁶⁹ Often this time is to provide treatments such as ABA that families have been unable to obtain in other ways (e.g. letter from Kristin Higgins).⁷⁰ A recent survey of parents with autism found that half of the mothers who were employed had cut back to be part time and half of those who were not employed had stopped working to care for child with autism.⁷¹ Again the letters from concerned citizens repeatedly describe individuals with careers who have withdrawn from the workforce to care for their child with autism.

Although only survey data were presented, it appears that families frequently choose to liquidate all their current resources including IRAs and savings in order to pay for early intervention.¹⁰ Respondents to that survey as well as some of the citizens providing testimony report that they have gone into bankruptcy or lost their homes. If this is frequently the case, the affected child is more likely to require state support as an adult without family being able to provide for them. Loss of family income may also impact the ability of the family to afford college for typically developing siblings who are likely to have less well paying jobs as adults without a college education.

Opponents present anecdotal information indicating that provision of the benefit and associated increase in benefits might increase the number of Pennsylvanians who are not insured. The information cited in multiple insurance company and insurance advocate submissions was that “it is estimated that for every 1% increase in private insurance premiums nationally, 400,000 people will become uninsured”⁷² or 14,000 to 16,000 Pennsylvanians.⁷³ The Pennsylvania Chamber of Business and Industry notes that each new mandated insurance benefit “increases by 1.5% the likelihood that a small business will not be able to afford or offer coverage,” but provides no source for this assertion.⁷⁴ It is important to note that employer health care costs

⁶⁹ Jarbrink K, fombonne E, Knapp M, (2003). Measuring the parental, service and cost impacts of children with autistic spectrum disorder: a pilot study. *Journal of Autism and Developmental Disorders*,33:395-492.

⁷⁰ Higgins letter: “In the meantime I researched everything I could on autism and started to learn ABA. . . I asked his school if they could give him more ABA therapy. They were very understaffed and could only offer 1 hour a day of which many days were skipped because they just couldn’t get to it. . . . At this point Aidan had been in school with BICU for 9 mths. The only words I heard him say are what I taught him using ABA. He still had all his other “negative” behaviors. I finally found a school which taught solely on the principals of ABA. After many meetings and much convincing, I finally got BCIU to fund and refer Aidan to the school. His progress is remarkable in the short time he has been there. . . . They have gotten rid of all of the “negative behavior”.. . These therapies basically saved our life.”

⁷¹ Sharp DL, Baker DL (2007). Financial issues associated with having a child with autism. *Journal of Family Economic Issues*,28:247-264.

⁷² From Highmark 10-4-2007 submission,pp10-11, citing 2003 study of mandates in New York state conducted by NovaRest Consulting.

⁷³ 10-2-2007 Independence Blue Cross Submission, p2, no citation is given for their statement

⁷⁴ PA Chamber letter 8-8-2007, page 2, no citation is given for their statement.

were described as expected to rise by 8.7% in 2008 in the absence of increased benefits.⁷⁵ The estimated ~ 1% increase in premiums associated with the proposed benefit would represent only 11% of the current increase.

Question 5. Where the proposed benefit would mandate coverage of a particular therapy, the results of at least one professionally accepted, controlled trial comparing the medical consequences of the proposed therapy, alternative therapies and no therapies.

The proposed benefit mandates that “treatment for autism spectrum disorders” shall include the following care prescribed, provided or ordered for an individual diagnosed with an autism spectrum disorder by a [licensed professional] if the care is determined to be medically necessary” (i.e., as defined by the bill: any care, treatment, intervention, service or item which is prescribed, provided or ordered by a licensed physician, licensed psychologist or certified registered nurse practitioner in accordance with accepted standards of practice and which will, or is reasonably expected to, do any of the following:

- i) prevent onset of . . . disability;
- ii) reduce or ameliorate the physical, mental or developmental effects of an illness . . . or disability;
- iii) assist to achieve or maintain maximum functional capacity in performing daily activities, taking into account . . . those functional capacities that are appropriate of recipients of the same age,

Including:

- i) psychiatric care,
- ii) psychological care,
- iii) rehabilitative care [which is defined to include applied behavioral analysis (ABA)];
- iv) therapeutic care [defined to mean services provided by licensed or certified speech therapists, occupational therapists or physical therapists];
- v) pharmacy care [defined to mean medications prescribed by a licensed physician or certified registered nurse practitioner and any health related services deemed medically necessary to determine the need or effectiveness of the medications];
- vi) any care, treatment, intervention, service or item for individuals with an autism spectrum disorder which is determined by the Department of Public Welfare, based upon its review of best practices of evidence-based research, to be medically necessary and which is published in the Pennsylvania Bulletin.”

Thus the only “*particular therapy*” specifically mentioned by the HB 1150 is applied behavioral analysis (ABA).

⁷⁵ Highmark submission of 10-4-2007, page 12 citing Hewitt Associates (full citation not provided)

There is extensive professionally accepted evidence supporting the efficacy of ABA compared to no or minimal therapies and to alternative therapies. The strongest evidence is provided by Eikeseth, Smith, Jahr and Eldevik (2002⁷⁶, 2007⁷⁷). Although the Eikeseth et al., 2002 paper was not supplied in the evidence submitted to the panel, the Eikeseth et al., 2007 paper explicitly refers the reader to it for additional information about methods and participant characteristics. In addition, the Panel's duty to determine whether all relevant research has been cited leads us to point out the Eikeseth et al., 2002 article. The two articles report on different phases of outcome in the same study. In this study, 25 children with autism between the ages of 4 and 7 were assigned to receive a minimum of 20 hours/week of either ABA treatment or eclectic treatment by an independent state funded autism specialist. Treatment assignment was based upon availability of qualified supervisors with no regard to child characteristics or parent preference. Treatment assignments were made over a 3 year period so cohort effects are likely to be minimal. Each child was integrated into a different school with their own individual therapists, so there were not treatment center effects.

The ABA therapy used the manual and videotapes developed by Lovaas but did not include any aversive contingencies. The treatment focused on very simple tasks such as responding to an adult and gradually progressed to more complex tasks such as conversing and making friends. Initially all treatment was individual, discrete trial format but later focused on generalization to the classroom setting. The therapists did not have prior training but received 10 hours of supervision weekly from supervisors who had a minimum of 1,500 hours of experience implementing ABA treatment and met recommended ABA qualification criteria⁷⁸ and 1-2 hours weekly with the team directors, who were psychologists, each of whom had 10 years experience or more implementing the UCLA treatment. In addition weekly 2 hour meetings were held with child, primary caretaker, therapists, supervisors, and director. Parental participation was also central with parents working along side therapists 4 hours per week during the first 3 months and then continuing the intervention in the home setting.

The comparison eclectic treatment was designed to meet best practices as outlined by Dawson & Oesterling.⁷⁹ This treatment incorporated elements from Project TEACCH, sensory motor therapies, and ABA. The specific interventions were individually selected for the child based on recommendations from a multidisciplinary team. The interventions were implemented on a 1 to 1 basis with the same therapist serving as an aid during classroom activities. The

⁷⁶ Eikeseth S, Smith T, Jahr E, Eldevik S, (2002). Intensive behavioral treatment at school for 4- to 7-year-old children with autism. A 1-year comparison controlled study. *Behavior Modification* 26:49-68. This article was not provided previously to PH4C but included as an appendix to this report.

⁷⁷ Eikeseth S, Smith T, Jahr E, Eldevik S, (2007). Outcome for children with autism who began intensive behavioral treatment between ages 4 and 7. A comparison controlled study. *Behavior Modification* 31:264-278.

⁷⁸ Smith T, Donahoe PA, Davis BJ, (2000). The UCLA treatment model. In S.L. Harris and J.S. Handelman (Eds.), *Preschool education programs for children with autism* (2nd edition, pp29-48). Austin, TX: Pro-Ed.

⁷⁹ Dawson G, Osterling J, (1997). Early intervention in autism. In M. J. Guralnick (Ed.), *The Effectiveness of Early Intervention* (pp. 307-326). Baltimore: Paul H. Brookes.

therapists received weekly, 2 hour consultations from the supervisors and same directors as provided leadership for the ABA intervention group.

Outcome assessments were performed by a blinded psychologist or psychological examiner with a master's degree in special education, both of whom had extensive experience with children with autism. The outcomes included standardized tests of general cognitive functioning (IQ), visual-spatial skills, language and adaptive behaviors. Treatment hours were 28 in the ABA group and 29 in the eclectic comparison group. Therapist education was similar for both groups. Mean intake IQ was 61.92 in the ABA group and 65.00 in the eclectic comparison group. On measures of language and adaptive behavior a similar pattern was observed with the ABA group showing numerically lower baseline values (including IQ 3.3 points lower, total language 8.2 points lower and adaptive behavior 4.2 points lower) for 10 of the 11 measures of interest. After 1 year of treatment, the ABA group improved mean IQ by 17 points (SD = 11), total language by 27 points (SD = 20), and adaptive behavior by 11 points (SD = 15). In contrast, the eclectic comparison group improved IQ by only 4 points (SD = 8) points, total language by 1 point (SD = 17), and adaptive behavior by < 1 (8) point. All of these between group differences in change from baseline scores were statistically significant at the (one-sided) $p < 0.01$ to 0.05 level. At end of the follow-up period the ABA group's scores were consistently higher than the eclectic group, but not significantly so.

The two treatments were then continued for nearly two more years. Three years after entering the study, the children were reassessed by blinded evaluators. The ABA group improved IQ from baseline by a total of 25 points, Vineland daily living skills by 9 points and Vineland communication by 20 points. The eclectic comparison group improved IQ by a total of 7 points, but showed decreases of 6 to 12 points on the Vineland subscales. In addition the ABA group showed fewer social problems, less aggression and fewer Vineland maladaptive behaviors than the eclectic group. Fifty-four percent (54%) of the ABA group and only 17% of the eclectic group scored within the normal range of IQ. Interestingly, IQ changed most dramatically early in ABA treatment and daily living skills and adaptive and social behaviors as reflected by Vineland scores changed most later in ABA treatment. A similar pattern was not observed in the eclectic comparison group.

In addition to this well-controlled study, there are a number of other studies comparing ABA to other treatments in a less rigorous way and in different treatment settings that also show fairly consistent evidence of benefit of ABA on cognitive functioning and ability to function in much more age-appropriate fashion. Three of these studies are discussed here. A study by Howard et al. (2005)⁸⁰ compared 29 preschool children receiving ABA (25-40 hours/week), 16 children receiving 30 hours/week of 1:1 or 1:2 eclectic intervention (combination of TEACCH, sensory integration and some ABA) and 16 children in a non-intensive 15 hour/week 1:6 group intervention (13 of whom also received speech therapy). The treatment each child received was determined by regional early intervention center but heavily considered parental preference. Treatment in the ABA group was provided by college students under direct supervision of a

⁸⁰ Howard JS, Sparkman CR, Cohen HG, Green G, Stanislaw H, (2005). A comparison of intensive behavior analytic and eclectic treatments for young children with autism. *Research in Developmental Disabilities*, 26:359-383.

master's level clinician with extensive ABA experience under the guidance of a Board Certified Behavior Analyst (PhD in psychology or speech therapist). Children were assessed after 7-14 months of treatment by independent contractors, but the contractors were not necessarily blind to the type of treatment received by the children. Intervention groups differed significantly at baseline with respect to age of diagnosis, age at onset of treatment, age at follow-up testing, and parents' education. The analyses of follow-up data attempted to control for these baseline imbalances. Children in the ABA group showed a 11pt (SD 15) gain on a composite cognitive scale and a 21 (11) month gain in communication skills, compared to a one point (SD 12) decrease in the cognitive measure and a 8 (10) month gain in communication in the intensive eclectic program and a 3 point (14) decrease in the cognitive measure and 10 (9) month gain in communication in the low intensity program. The differences with respect to each of these follow-up measures between the ABA group and the two comparison groups combined are statistically significant at the $p < 0.05$ level. In addition, more than half of the children in the ABA group showed learning rates above normal after the intervention whereas very few in the other two groups did.

Although not supplied in the documentation, the Panel's charge to determine whether all relevant research has been cited leads us to point out a randomized controlled trial conducted by Smith, Groen and Wynn⁸¹ that provides nearly as strong evidence as the Eikeseth et al. study. In the Smith, Groen and Wynn study, 28 children with ASDs, mean age 3 years, were randomly assigned to receive intensive ABA which included a parent component for 5 hours/week for the first 3 months or parent training in ABA methods for five hours/week for 3 to nine months. In both condition's Lovaas's 1981 manual was utilized but did not include the use of negative consequences (aversives) except for a very brief period in the initiation of the study. The mean therapy received by the ABA group was 24.5 hours/week during the first year, with gradually reducing hours in the second and third years. ABA treatment was administered by college students who were supervised by the authors who had a combined total of 10 years experience under Lovaas's supervision. Further these student therapists were required to pass written tests on the treatment methodology and a standard behavioral test of them administering the intervention. Only therapists with a minimum of 1,500 hours of experience were allowed to become supervisors. The control group did not receive further intervention from the study once parent training was completed.

Participants were assessed at baseline and when they were 7-8 years old (2-3 years following completion of the intervention). Assessments were done by a clinician who was blinded to the treatment each participant had received. At baseline, 82% of the children were nonverbal and none achieved a basal score on the Stanford-Binet IQ test; mean baseline IQ in both groups was 51. At follow-up, children in the ABA group had a mean IQ of 66 (increase of 16 points) while those in the parent training group had a mean IQ of 50 (1 point decline). Total language scores increased by 58 points in the ABA group (29 to 87) and by 31 points in the parent group (30 to 61). Several children in the ABA group showed ceiling effects that may have reduced the apparent differences between the two groups. Six of the 15 children in the ABA group (40%) were in regular education (4 without an aid) whereas only 1 of the 13 in the parent

⁸¹ Smith T, Groen AD, Wynn JW, (2000). Randomized trial of intensive early intervention for children with pervasive developmental disorder. *American Journal on Mental Retardation* 105:269-285.

group (8%) was in regular education and had an aid. All of these changes were statistically significant. The authors speculate that the lower intensity of this program may account for the less dramatic response observed compared to Lovaas's initial study.

A similar study was conducted by Cohen and colleagues.⁸² They studied 21 children younger than 3 years of age who received 35-40 hours/week of ABA therapy for three years and 21 age and IQ matched children in a variety of community early intervention services with fewer than 9 hours/week ABA. Treatment assignment was not randomized but rather based on parent preference. Outcome assessments were conducted by independent examiners who appear blinded to the treatment each child received. At baseline, the ABA group had numerically higher IQ (61.6 vs 59.4), nearly identical language skills and Vineland adaptive behavior scores. The mean IQ increased by 25 points in the ABA group and 14 points in the control group, language composite increased by 20 points in the ABA group and 9 points in the comparison group, and Vineland adaptive behavior composite increased by 9 points in the ABA group but declined by 4 points in the comparison group. Both of these comparisons were statistically significant.

Findings from these studies consistently show that focused ABA programs can provide outcome advantages over equally intense eclectic programs even when those programs incorporate ABA techniques.

Question 6. Where the proposed benefit would mandate coverage of an additional class of practitioners, the results of at least one professionally accepted, controlled trial comparing the medical results achieved by the additional class of practitioners and those practitioners already covered by benefits.

The Panel's understanding of HB 1150 indicates that at the clinical decision-making level, it does not extend coverage to "an additional class of practitioners" who are not already planning and overseeing the implementation of treatment or other services to children with ASD. Specifically, HB 1150 amends section 635.2 of Pennsylvania's Insurance Company Law of 1921 to indicate that with respect to autism spectrum disorders:

(f) (8) "Medically necessary" means any care, treatment, intervention, service or item which is prescribed, provided or ordered by a licensed physician, licensed psychologist or certified nurse practitioner in accordance with accepted standards of practice and which will, or is reasonably expect to, do any of the following:

- (i) Prevent or the onset of an illness, condition, injury, or disability.*
- (ii) Reduce or ameliorate the physical, mental or developmental effects of an illness, condition, injury or disability.*
- (iii) Assist to achieve or maintain maximum functional capacity in performing daily activities, taking into account both the functional capacity of the recipient and*

⁸² Cohen H, Amerine-Dickens M, Smith T, (2006). Early intensive behavioral treatment: replication of the UCLA model in a community setting. *Developmental and Behavioral Pediatrics*, 27:S145-S155.

those functional capacities that are appropriate of recipients of the same age.”
(HB 1150, p. 5, lines 18-30 and p. 6, lines 1-3; italics added).

The licensed and/or certified professionals who are empowered by HB 1150 to plan and oversee ASD treatment are the traditional groups who authorize and provide such treatment, and as such do not constitute an “additional class.”

One potential issue that the panel sees with respect to “new” practitioners, however, may be with non-clinical personnel who directly provide applied behavioral analysis (ABA) treatment. Several peer-reviewed, controlled studies documenting the efficacy of ABA were included among the submitted evidence. The three studies described in detail in Question 5, all provide detailed descriptions of the content and procedures of ABA treatment and the training required for the therapists working most directly with the children⁸³. In this study, the ABA intervention was implemented in schools, by teachers and teacher aides who were trained and supervised by experienced therapists. Additionally, parental participation was a critical element of the treatment, and parents were also trained by therapists in implementing the one-to-one elements of the treatment. As a result, these studies document empirically that teachers, teacher aides, and parents with training and oversight by experienced therapists can achieve significant results implementing ABA treatment in real-world settings. This study clearly documents that non-clinical providers can be successful implementing ABA with adequate training and supervision by experienced clinicians.

Additional information related to non-clinical providers’ ability to implement ABA treatment for ASD is provided in the answer to part C of Question 8 (pp. 37-38 of this report).

Question 7. The results of any other relevant research.

Pursuant to the charge of the panel to determine ‘Whether or not all relevant research respecting the proposed mandated benefit has been cited in the documentation,’ the Panel feels that two studies not included in the evidence are particularly relevant because they report scientifically rigorous evaluations of ABA. These two articles Eikeseth et al., 2002⁸⁴ and Smith, Groen, and Wynn, 2000⁸⁵ are provided with this report. The findings from the Eikeseth et al.

⁸³ Eikeseth S, Smith T, Jahr E, Eldevik S, (2002). Intensive behavioral treatment at school for 4- to 7-year-old children with autism. A 1-year comparison controlled study. *Behavior Modification* 26:49-68. ; Eikeseth S, Smith T, Jahr E, Eldevik S, (2007). Outcome for children with autism who began intensive behavioral treatment between ages 4 and 7. A comparison controlled study. *Behavior Modification* 31:264-278.; Smith T, Groen AD, Wynn JW, (2000). Randomized trial of intensive early intervention for children with pervasive developmental disorder. *American Journal on Mental Retardation* 105:269-285.; Cohen H, Amerine-Dickens M, Smith T, (2006). Early intensive behavioral treatment: replication of the UCLA model in a community setting. *Developmental and Behavioral Pediatrics*, 27:S145-S155.

⁸⁴ Eikeseth S, Smith T, Jahr E, Eldevik S, (2002). Intensive behavioral treatment at school for 4- to 7-year-old children with autism. A 1-year comparison controlled study. *Behavior Modification* 26:49-68.

⁸⁵ Smith T, Groen AD, Wynn JW, (2000). Randomized trial of intensive early intervention for children with pervasive developmental disorder. *American Journal on Mental Retardation* 105:269-285.

article are summarized in the response to Question 5, pages 27 and 28, and the findings from the Smith et al. article are summarized in Question 5, page 29. Other relevant empirical findings of which the panel is aware but that were not included in the evidence submitted are discussed in the answer of the questions to which they relate.

Question 8. Evidence of the financial impact of the proposed legislation

As noted in a recent paper by Garber, published in Health Affairs, the tension between technology diffusion and expenditures is common in deliberations about mandated health insurance benefits.⁸⁶ As the materials submitted by proponents and opponents of HB 1150 reveal, there is a related tension between the desire to address the growing need of Pennsylvania's children with ASD by employing evidence based practices (EBPs) and the sources of future expenditures for care to many of the children who are now or would in the future be eligible for mandated benefits.

The task in determining the balance in these tensions requires a comprehensive assessment of the evidence that has been submitted to PHC4 to determine at least two things:

- ❑ if there are meaningful medical and quality of life (QOL) results predicted for the children, their families and the Commonwealth pursuant to application of the mandated benefit, and
- ❑ If the estimated increase in health care costs is feasible.

As Garber notes, the burden of proof is typically on the proponents. In the case of the evidence submitted to PHC4, while this has not been explicitly stated as an assumption, the relative weight of evidence provided by each party would seem to affirm that notion. The proponents have submitted volumes of testimony, research papers and data analyses. In contrast, the opponents submitted fewer than a dozen letters that in some cases reference industry reports, and in others provide brief estimations of potential premium increases.

The private health insurance industry is familiar with standardized evidence-rating schemes, such as the USPSTF, and maintains a national resource to determine the safety and efficacy of treatment innovations in the Blue Cross Blue Shield Association (BCBSA) Technology Evaluation Center.⁸⁷ The submissions from the proponents, including academic experts, public policymakers, governmental agencies, legislative committees and foundations provide an examination of the peer reviewed scientific evidence on services to children with ASD. The proponents have, wittingly or not, addressed in their submissions to PHC4 the decision-making criteria employed by the BCBSA Technology Evaluation Center, including:

1. Receipt of final Government approval of the treatment or device

⁸⁶ Garber AM. Evidence-based coverage policy. Health Affairs 2001; 20(5):62.

⁸⁷ Garber AM. Evidence-based coverage policy. Health Affairs 2001; 20(5):62.

2. Effect on health outcomes
3. Improvement of net health outcomes
4. Treatment or device is as beneficial as alternatives, and
5. Results are attainable outside of research settings.⁸⁸

Summary of the Proposed ASD Benefit

House Bill 1150 requires private insurers to provide “coverage for diagnosis and treatment of Autism Spectrum Disorders” in children up to age 21.⁸⁹ The Legislation sets a cap on the mandated coverage of \$36,000 per annum per child.⁹⁰ Coverage is tied to “medical necessity”, which is to be defined based on evidence.⁹¹ Applied Behavioral Analysis (ABA) is cited as a covered evidence based practice. HB 1150 further directs the Pennsylvania Department of Welfare (DPW) to establish credentialing standards for practitioners and ensure parity between private insurance and government programs.⁹² The mandated benefit is subject to the same co-pays, deductibles and co-insurance provisions as apply to other insurance benefits⁹³ and managed care continuity provisions for non-participating providers⁹⁴ also apply.

House Bill 1150 recognizes the legitimacy of private insurance demand for coverage of services to children with ASD and attempts to eliminate supply side constraints through provisions of the mandate that remove previous benefit exclusions, address network certification standards, and provide continuous State support to cover co-pays, deductibles and/or co-insurance provisions that might create barriers for families who would use the private insurance ASD benefit.

A. Impact on increase or decrease in cost for treatment or service

⁸⁸ Garber AM. Evidence-based coverage policy. *Health Affairs* 2001; 20(5):62.

⁸⁹ Autism Spectrum Disorders Coverage, H. 1150, Lines 6-8, The General Assembly of Pennsylvania, Session of 2007. Amendment to Pennsylvania Code P.L. 682, No. 284. The Insurance Company Law of 1921, May 17, 1921.

⁹⁰ Autism Spectrum Disorders Coverage, H. 1150, Lines 22-25, The General Assembly of Pennsylvania, Session of 2007. Amendment to Pennsylvania Code P.L. 682, No. 284. The Insurance Company Law of 1921, May 17, 1921.

⁹¹ Autism Spectrum Disorders Coverage, H. 1150, Lines 18-30 and 1-13, The General Assembly of Pennsylvania, Session of 2007. Amendment to Pennsylvania Code P.L. 682, No. 284. The Insurance Company Law of 1921, May 17, 1921.

⁹² Autism Spectrum Disorders Coverage, H. 1150, Lines 14-30, The General Assembly of Pennsylvania, Session of 2007. Amendment to Pennsylvania Code P.L. 682, No. 284. The Insurance Company Law of 1921, May 17, 1921.

⁹³ Autism Spectrum Disorders Coverage, H. 1150, Lines 13-17, The General Assembly of Pennsylvania, Session of 2007. Amendment to Pennsylvania Code P.L. 682, No. 284. The Insurance Company Law of 1921, May 17, 1921.

⁹⁴ Autism Spectrum Disorders Coverage, H. 1150, Lines 16-26, The General Assembly of Pennsylvania, Session of 2007. Amendment to Pennsylvania Code P.L. 682, No. 284. The Insurance Company Law of 1921, May 17, 1921.

DPW reports estimate that the average annual per child cost of the Commonwealth's Medical Assistance (MA) benefit, which includes Applied Behavioral Analysis (ABA), is \$14,300 in FY2008/2009. This sum is based on the following assumptions: 2004 actual costs, adjusted by a 4% inflation factor per year. DPW reports that it served 13,800 children with ASD in 2007, 7,400 of whom were MA beneficiaries and 6,400 of whom were privately insured and covered by PH-95 provisions because their private insurers excluded coverage for the ASD diagnoses.⁹⁵ Those 13,800 served children represent the treated prevalence in Pennsylvania, while the total prevalence of Pennsylvania children with ASD under age 21 is estimated at 22,316 based on CDC estimates that 1 on 150 children has ASD conditions.⁹⁶

DPW further reports expected decreases in costs to the Commonwealth with implementation of the HB 1150 provisions, assuming that the 50% state match to federal Medicaid reimbursements will accrue for an estimated 25% of the MA-covered children served who are privately insured and an estimated 80% of the PH-95-covered children served who are privately insured in full benefit, non-ERISA plans. There are an estimated 1,900 and 5,100 children in these two respective groups.⁹⁷

DPW engaged its Medicaid actuarial firm, Mercer, to study the potential cost savings to the Commonwealth. Mercer concluded, employing the DPW assumptions and estimates noted in the preceding paragraphs, that the Commonwealth would save approximately \$22.2 million in the first year and \$89.3 million over four (4) years.⁹⁸

Pennsylvania insurers' views on the cost impact of the mandated ASD benefit are contained in a series of letters from individual companies and industry organizations. There are a number of points made in narrative form, as listed below, however these were not accompanied by quantified assumptions or estimates, except for several insurers' estimates of premium increases that assume maximum benefit use to the \$36,000 per annum cap by either the treated prevalence group or the universe of all insured children with ASD, as will be reported in more detail later in this review in Section E. Pennsylvania insurers state that costs will increase as a result of implementation of HB 1150. For example:

- BCNEPA indicates that HB 1150 is an attempt by the Commonwealth to cost shift to the private insurers⁹⁹

⁹⁵ Estimated fiscal impact of HB 1150 (PN #2237). Pennsylvania Department of Public Welfare 2007; Harrisburg, PA.

⁹⁶ CDC Autism and Developmental Disabilities Monitoring Network Surveillance Year 2002 Principal Investigators, 2007. Prevalence of Autism Spectrum Disorders—Autism and Developmental Disabilities Monitoring Network Surveillance, 14 sites, United States, 2002. Morbidity and Mortality Weekly Report 56/SS-1:12-28

⁹⁷ Estimated fiscal impact of HB 1150 (PN #2237). Pennsylvania Department of Public Welfare 2007; Harrisburg, PA.

⁹⁸ Ibid

⁹⁹ Blue Cross of Northeastern Pennsylvania Letter of 10-04-07 from Kimberly Kockler to Flossie Wolf at PHC4

- ❑ Highmark provides its 14 May 2007 Medical Policy which “excludes care for the diagnosis of autism” that “extends beyond traditional medical management or provides for environmental change”¹⁰⁰ and further states that the mandate “will most certainly lead to an increase in utilization of autism services”.¹⁰¹
- ❑ IBC states that HB1150 would cost health plans in requiring them to “pay unlicensed providers”, despite the Bill’s charge to DPW to set standards for and certify covered autism professionals¹⁰²
- ❑ Some insurers assume, despite the evidence presented by DPW¹⁰³ on average annual per treated child costs for use of current MA and PH-95 benefits (which cover ABA), that the universe of insured children with ASD will each use the maximum benefit, exceeding by more than double those costs that the Commonwealth now incurs per treated child¹⁰⁴
- ❑ Concerned about rapid growth in the ASD diagnoses
- ❑ Highmark argues that “Behavioral Therapies” are not medically necessary services¹⁰⁵, however the Motilawa study (cited in response to Questions 3 at page 21 of this document as the best quality of the cost studies submitted) provides sound evidence of the cost effectiveness of intensive behavioral interventions¹⁰⁶
- ❑ The Insurance Federation of Pennsylvania (IFP) cites increased costs associated with a perceived inability “to audit the quality of care” and requirements to “accept DPW providers” into private insurance networks; the IFP statement cites a minimum of \$22M in increased costs (equal to “Speaker O’Brien’s estimate of the savings to the Commonwealth”, as cited in Attachment A of the Speaker’s submission) and a high end estimate based on the statement that “insurance actuaries agree that the cost impact will be in the 2 – 6% range.”¹⁰⁷

Proponents submitted a number peer reviewed research articles on ABA and EIBI, among other behavioral therapies, and included in their submissions cost-benefit analyses and outcome studies. In a 2006 article, David Mandell cites 10 years of research articles that suggest substantial improvements in functioning among children with ASD after behavioral rather than

¹⁰⁰ Highmark Letter and Submission of 10-04-07 from Michael Wartel to Flossie Wolf at PHC4

¹⁰¹ Ibid

¹⁰² Independence Blue Cross Letter of 10-02-07 from Mary Ellen McMillen to Flossie Wolf at PHC4

¹⁰³ Estimated fiscal impact of HB 1150 (PN #2237). Pennsylvania Department of Public Welfare 2007; Harrisburg, PA.

¹⁰⁴ Highmark Letter and Submission of 10-04-07 from Michael Wartel to Flossie Wolf at PHC4

¹⁰⁵ Ibid

¹⁰⁶ Motilawa SS, Gupta S, Lilly MB, Ungar WJ, Coyte PC. The cost-effectiveness of expanding intensive behavioural intervention to all autistic children in Ontario. *Healthcare Policy*. 2006;1:135-151.

¹⁰⁷ Insurance Federation of Pennsylvania letter of 10-04-07 from John Doubman to Flossie Wolf at PHC4

medical interventions.¹⁰⁸ In one cited study, 47% of the children in the behavioral treatment conditions achieved “normal intellectual and educational functioning” as compared to 2% of those who received standard medical and educational benefits only.¹⁰⁹ Higher levels of functioning are associated with lower health care costs. Children with Autism who are lower functioning are more likely to use higher amounts of health care services for outpatient visits, medication and inpatient stays. In another 2006 article, Liptak et al. report on data from three (3) national health surveys conducted in 1999 and 2000 that reveal health care utilization and expenditures for children with Autism. Although there are limitations in two of these data sets as discussed earlier in this Panel Report in answer to Question 3, findings from this study indicate that children with Autism, who most often lack coverage for effective behavioral therapies, use substantially more outpatient visits and use physician time longer during each visit than, for example, children with mental retardation.¹¹⁰ Length of outpatient visits for children with Autism in the study were similar to those of children with depression, and approximately 24 % of the study group used medications, the most common of which was risperidone.¹¹¹

In 2004, Mandell reported a study of publicly and privately insured Pennsylvania children with ASD, examining their rates of inpatient psychiatric hospital use. The chief finding of the study is that there was significant separation in rates of hospitalization between children who had earlier diagnosis and received Early Intervention and those who did not; the late diagnosed group who did not receive early behavioral interventions had significantly higher rates of self-injury and aggression.¹¹² In this Pennsylvania study, Mandell found significant variation in results across the Counties, which he interpreted to reveal variation in health system factors that drove the differences, rather than differences inherent to the population of the Commonwealth’s children with ASD. Mandell separately studied use of psychotropic medications nationally among children with ASD and found that as many as 56% are prescribed one or more psychotropic drugs and as many as 20% of these children are prescribed three or more drugs concurrently.¹¹³

Jacobson and Mulick found that Early Intensive Behavioral Intervention (EIBI) provided in British Columbia and targeted to identified deficits demonstrated “substantial and sustainable benefits to children with PDD” and “substantial per capita cost savings” over an individual’s

¹⁰⁸ Mandell D, Cao J, Ittenbach R, Pinto-Martin J. Medicaid expenditures for children with autistic spectrum disorders: 1994-1999. *Journal of Autism and Developmental Disorders* 2006; 36(4).

¹⁰⁹ Mandell D, Cao J, Ittenbach R, Pinto-Martin J. Medicaid expenditures for children with autistic spectrum disorders: 1994-1999. *Journal of Autism and Developmental Disorders* 2006; 36(4).

¹¹⁰ Liptak GS, Stuart T, Auinger P. Health care utilization and expenditures for children with autism: Data from U.S. national samples. *Journal of Autism and Developmental Disorders*. 2006; 36:871-879.

¹¹¹ Ibid

¹¹² Mandell D, Cao J, Ittenbach R, Pinto-Martin J. Medicaid expenditures for children with autistic spectrum disorders: 1994-1999. *Journal of Autism and Developmental Disorders* 2006; 36(4).

¹¹³ Mandell DS, Morales KH, Marcus SC, Stahmer AC, Doshi J, Polsky DE. Psychotropic medication use among Medicaid-enrolled children with autism spectrum disorders. *Pediatrics*. 2008; 121:e441-e448.

lifetime.¹¹⁴ Jacobson, Mulick and Green further reported a study using Pennsylvania data to study EIBI in which they found EIBI-related cost savings of approximately \$187 thousand to \$203 thousand for children served between the ages of 3 and 22; and, savings of \$656 thousand to \$1,082 million between the ages of 3 and 55.¹¹⁵ Initial cost differences for three (3) years of EIBI were estimated at \$33 thousand and \$50 thousand per child per year; the authors suggest that these figures represent a modest impact on cost/benefit ratios.

Ganz, as cited in response to Question 3 at page 14 of this document, estimated average per capita discounted lifetime cost for individuals with ASD who were untreated at \$3.2M per person.¹¹⁶ Ganz' analysis is more specific than other studies noted in that it estimates costs for each care component in each 5-year age category, summarizing a discounted lifetime behavioral therapy cost of \$206,333 for treated individuals with ASD diagnoses.¹¹⁷

The HB 1150 proponents also submitted studies that document out of pocket family expenditures for services provided to children with ASD. Jabrink et al conducted a pilot study in England that found total cost impacts to families of between 689L and 855L.¹¹⁸ Sharpe and Baker found that unreimbursed medical costs cause significant financial problems for families who have a child with Autism, suggesting that families will put themselves at financial risk in order to get effective Early Intervention services to help their children.¹¹⁹

The private insurers state that the mandated ASD benefit will require them to pay for more services for their plan member families who have a child with ASD.¹²⁰ HB 1150, also makes provisions for PH-95 to cover certain insurance related out of pocket expenses, it is reasonable to anticipate that there will be a decrease in family costs.

As noted, several of the Pennsylvania insurers cited the rapid growth in the prevalence of ASD as one of the reasons that they did not support the HB 1150 benefit. Leslie and Martin evaluated data on one (1) million covered lives from the Thompson/Medstat Market Span Database, tracking the increase in ASD diagnoses and treated prevalence between the years 2000 and 2004. The authors report that ASD diagnoses increased from 1.8% to 2.9% of these insured

¹¹⁴ Jacobson JW, Mulick JA. System and Cost Research Issues in Treatments for People with Autism. *Journal of Autism and Developmental Disorders* 2000; 30(6).

¹¹⁵ Jacobson JW, Mulick JA, Green G. Cost benefit estimates for early intensive behavioral intervention for young children with autism—general model and single state case. *Behavioral Interventions* 1998; 13:201-226.

¹¹⁶ Ganz ML. The lifetime distribution of the incremental societal costs of autism. *Archives of Pediatrics and Adolescent Medicine*. 2007; 161:343-349.

¹¹⁷ Ibid

¹¹⁸ Jabrink K, Fombonne E, Knapp M. Measuring the Parental, Service and Cost Impacts of Children with Autistic Spectrum Disorder: A Pilot Study. *Journal of Autism and Developmental Disorders* 2003; 33(4).

¹¹⁹ Sharpe DL and Baker DL. Financial issues associated with having a child with autism. *Journal of Family Economic Issues* 2007; 28:247-264.

¹²⁰ Private Insurers Letters, including BCNEPA Letter of 10-04-07; Highmark Letter of 10-04-076; IBC Letter of 10-02-07; CBC Letter of 10-03-07 and IFP Letter of 10-04-07

children and adolescents, while treated prevalence increased from 9.5 per 10,000 children in 2000 to 19.2 per 10,000 in 2004, and average cost of ASD treatment increased from \$5,316 in 2000 to \$6,706 in 2004.¹²¹ Treated prevalence increased by 101.1%, exceeded only by the 106% increase in Bipolar diagnoses among these insured children during the five year period.

It is fair to ask whether or not the submitted evidence provides a complete picture of demand for the mandated ASD benefit. As noted in response to Question 1 of this document, PH-95 requirements for diagnosis and disability preclude those children of higher functional levels, who may benefit greatly from the mandate, from accessing MA benefits at present. Since the private insurers in Pennsylvania do not cover the behavioral therapies covered by PH-95, it is unlikely that the demand for this care has been measured among covered beneficiaries who do not meet the PH-95 disability requirements. It is likely, however, that these individuals have been using some benefits that are covered under their family policies, and a cost offset might be anticipated if the mandate were in effect and there was substitution of behavioral therapies for some presently utilized outpatient, medication and/or inpatient services.

The Motilawa study cited above provides sound evidence of cost effectiveness, based on data from Ontario, estimating 18 year cost offsets for persons with autism who are treated for 3 years with behavioral interventions at \$208,500.¹²² The Jacobson, Mulick and Green study cited earlier uses Allegheny County, Pennsylvania data and finds levels of EIBI cost effectiveness similar to the Motilawa study, at \$187,000 to \$203,000 for children served between the ages of 3 and 22 and, savings of \$656 thousand to \$1.082 million between the ages of 3 and 55.¹²³ Initial cost differences for three (3) years of EIBI were estimated at \$33 thousand and \$50 thousand per child per year; the authors suggest that these figures represent a modest impact on cost/benefit ratios.¹²⁴

The Boudier submission on behalf of the Vista Foundation is further evidence addressing cost utility and variation analyses, using Pennsylvania data.¹²⁵ The Vista Foundation assumed cost effectiveness as estimated in the research literature cited, while analyzing a range of scenarios employing DPW, research and Pennsylvania private insurers' prevalence, utilization and premium estimates. The results of the Vista Foundation analyses indicate modest premium cost increases for the HB 1150 ASD benefit of \$3.45 PM/PM to \$4.10 PM/PM.¹²⁶ The Vista Foundation analyses, with premium cost increases no higher than 1%, stand in contrast to the

¹²¹ Leslie DL and Martin A. Health care expenditures associated with autism spectrum disorders. *Archives of Pediatric Adolescent Medicine* 2007; 161(4):350-355.

¹²² Motiwala SS, Gupta S, Lilly MB, Ungar WJ, Coyte PC. The cost-effectiveness of expanding intensive behavioural intervention to all autistic children in Ontario. *Healthcare Policy*. 2006;1:135-151

¹²³ Jacobson JW, Mulick JA and Green G. Cost-benefit estimates for early intensive behavioral intervention and special education for children with autism: General model and single state case. *Behavioral Interventions*, 1998; 13, 201-226

¹²⁴ Ibid

¹²⁵ Boudier, JN. In Response to the Notice in re Mandated Benefits Pertaining to HB 1150 of 2007. Vista Foundation 2007; pp. 1-17 and Exhibits A-E.

¹²⁶ Ibid

higher end of the ranges cited by the Pennsylvania private insurers, for which detailed analyses were not presented to the Pennsylvania Health Care Cost Containment Commission.

B. Extent to which similar mandated benefits in other states affected charges, costs and payments for services

Mandates are commonly employed to correct health care market inequities. According to the materials submitted to PHC4, eight (8) states have legislated mandates designed to provide specialty health care benefits to persons who are diagnosed with ASD, including: GA, IN, KY, MD, NY, SC, TN and TX.¹²⁷ ASD mandates are typically focused on children. Among the eight (8) States, coverage reportedly varies from ages 3 to 21 to ages 3 to 16.¹²⁸ Service prescriptions also vary in amount, type and duration, with the majority of states prescribing coverage of ABA, EIBI and or DTT. And, annual caps on benefit costs also vary; KY employs a \$6 thousand cap while SC has a \$50 thousand annual cap on ASD benefits.

Parity is similar to a mandate in that it is designed to correct health care market inequities, however parity is explicitly focused on eliminating discrimination in health care coverage that apply to a particular diagnostic and/or beneficiary group. Parity typically focuses on equity in benefits, rather than prescribing a benefit, calling for treatment of the target health condition, diagnostic or beneficiary group that is equal to that of other covered conditions, diagnoses or beneficiary groups. Because of long standing discrimination in coverage, copays and caps applied to mental and substance use conditions, psychiatric diagnoses and behavioral health services, parity initiatives have been underway in the State Legislatures and the United States Congress for more than 20 years. Mental illness parity coverage is reported in 11 states, including: CA, CO, CT, DE, IL, IA, KS, LA, ME, MT, NH, NJ and VA.¹²⁹ Passage of parity legislation has provided one opportunity for inclusion of ASD diagnoses, which are listed in the fourth edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-IV).

According to the report published by the Council on Affordable Health Insurance (CAHI) in 2007, mandated or parity coverage in CO, DE, GA, IA, IN, KY, MD, NJ, NY and TN “raised costs by less than one (1) percent”.¹³⁰ Insurers point out that these cost impact findings are for mandates that differ from the HB 1150 mandate. Autism Speaks submitted a report on HB 1150 indicating that three (3) states ASD mandates are quite similar to the HB 1150 mandate: SC, TN and TX. Reportedly, South Carolina’s mandate covers behavioral therapies for children up to 16 years of age with a cap of \$50 thousand; Tennessee covers ABA for all ages with the same cap as applies to any other health condition; and Texas covers ABA for children from 3 to 5 years of

¹²⁷ Various authors pursuant to the John Warner National Defense Authorization Act for Fiscal Year 2007. Report and plan on services to military dependent children with autism. Department of Defense 2007.

¹²⁸ Various authors pursuant to the John Warner National Defense Authorization Act for Fiscal Year 2007. Report and plan on services to military dependent children with autism. Department of Defense 2007.

¹²⁹ Various authors pursuant to the John Warner National Defense Authorization Act for Fiscal Year 2007. Report and plan on services to military dependent children with autism. Department of Defense 2007.

¹³⁰ Bunce VC and Wieske JP. Health insurance mandates in the states 2005. Council of Affordable Health Insurance 2005.

age, again with same cap as applies to any other health condition.¹³¹ As cited above, the CAHI Report includes the Tennessee mandate as one that had raised costs by less than one (1) percent, a mandated benefit that covers ABA for all ages with the same cap as applies to other health conditions.

Other cost and payment impact studies submitted to PHC4 include:

- ❑ California Health Policy Roundtable Brief, published in July 2002, states that mandated services that are “preventive” in nature can mitigate other long term health costs, thereby mitigating the cost of the mandate¹³²
- ❑ A Canadian study of the cost effectiveness of expanding Intensive Behavioral Interventions (IBI) to all children between the ages 2 and 5 with ASD in Ontario indicates gains in dependency-free years to age 65, with reduced support costs and increased cost savings and productivity¹³³
- ❑ In a study reported in 2007, analyses were performed comparing the cost impact of eighteen (18) years of Special Education to three (3) years of Discrete Trial Training (DTT) as an EIBI; finding that DTT minimized the need for Special Education, saving \$208,500 per child over 18 years and \$2.09 billion for an estimated 10,000 eligible children¹³⁴
- ❑ Although the cost offset to EIBI noted in the study above was calculated for Special Education, other authors note that failure to attain more normal functioning in mainstream academic settings is associated with dysfunction and disability¹³⁵
- ❑ A study by the New Jersey Mandated Benefits Advisory Commission, reported in 2006, evaluated the impact of the ASD mandated benefit contained in Assembly Bill A-999, finding that the cost impact on a family health insurance policy was approximately \$10.17 per month¹³⁶

¹³¹ Autism Speaks Letters and Comments in Support of HB 1150; Attachments of Research Studies

¹³² Cubanski J and Schauffler HH. California Health Policy Roundtable Issue Brief: Mandated Health Insurance Benefits: Trade Offs Among Benefits, Coverage, and Costs? July 2002.

¹³³ Motiwala SS, Gupta S, Lilly MB, Ungar WJ, Coyte PC. The cost-effectiveness of expanding intensive behavioural intervention to all autistic children in Ontario. *Healthcare Policy* 2006;1(2):135-151.

¹³⁴ Chasson G, Harris G, Neely W. Cost comparison of early intensive behavioral intervention and special education for children with autism. *Journal of Child and Family Studies* 2007; 16(3):401-414.

¹³⁵ Leslie DL and Martin A. Health care expenditures associated with autism spectrum disorders. *Archives of Pediatric Adolescent Medicine* 2007;161(4)350-355.

¹³⁶ New Jersey Mandated Health Benefits Advisory Commission. A study of Assembly Bill A-999. Available at http://nj.gov/dobi/mhbac/070314_A999rpt_MHBAC.pdf

- According the Kaiser Family Foundation (KFF) average costs in 2007 for group family health insurance coverage in the United States was \$1,008 per month¹³⁷

ASD related dysfunction and disability is associated with increased use of outpatient services, psychotropic medications and psychiatric inpatient treatment. Psychotropic medication use and histories of psychiatric hospitalization are associated with high care costs and co-occurring chronic health conditions, as well as long term use of residential treatment and disability support services. The preponderance of evidence submitted indicates that the premium cost impact of Pennsylvania's mandated ASD benefit will be in the range of one (1) to one and one-half (1 ½) percent. Based on the KFF reports on average family health insurance premiums of \$1,008 per month, the range of premium increase would be between \$10.08 and \$15.12 per month.

C. Extent to which the proposed benefit would increase the appropriate use of treatment services

As outlined at the beginning of this review, House Bill 1150 requires private insurers to provide "coverage for diagnosis and treatment of Autism Spectrum Disorders" in children up to age 21, with a cap on the mandated coverage of \$36,000 per annum per child. Coverage is tied to services that are evidence based and medically necessary and Applied Behavioral Analysis (ABA) is cited as covered evidence based practice. Moreover, HB 1150 anticipates the challenges and barriers to access posed by inadequate provider networks, disruption in continuity of care and out of pocket costs associated with use of insurance. Therefore, HB 1150 directs the Pennsylvania Department of Welfare (DPW) to establish credentialing standards for practitioners, and ensure parity between private insurance and government programs with provisions that the mandated ASD benefit is subject to the same co-pays, deductibles and co-insurance provisions as apply to other insurance benefits and managed care continuity provisions for non-participating providers.

Opponents of the ASD mandate indicate that the benefit will increase use of services because at least ABA and related behavioral therapies are not presently covered:

- Capitol Blue Cross (CBC) notes that it covers 30 days of inpatient care and 60 days of outpatient care per benefit period, but does not cover behavioral therapy¹³⁸
- Highmark notes that it does cover "evidence based medical services" scientifically proven to improve ASD, but excludes "behavior modification and training", and further states that: "Historically, Highmark has found that whenever a service becomes eligible for insurance coverage, utilization of that service or benefit immediately increases."¹³⁹

¹³⁷ Health insurance premiums rise 6.1 percent in 2007, less rapidly than in recent years but still faster than wages and inflation. Kaiser Family Foundation. September 11, 2007. Available at <http://www.kff.org/insurance/ehbs091107nr.cfm>.

¹³⁸ Capital Blue Cross Letter of 10-03-07 from Robert Baker, Jr. to Flossie Wolf at PHC4

¹³⁹ Highmark Letter and Submission of 10-04-07 from Michael Wartel to Flossie Wolf at PHC4

- ❑ Blue Cross of Northern Eastern Pennsylvania (BCNEPA) indicates that it has no experience with the ASD population and that the current deficiencies in the MA program are not related to a lack of coverage, but to “a structural or network deficiency”, however BCNEPA reports that “it is unlikely that the mandate included in HB 1150 will increase the appropriate use of autism treatment”, because of the coverage already provided under the Commonwealth’s MA program. Despite this assertion, BCNEPA argues that the benefit will cost \$12M for 1 in 150 of its 600,000 members, each of whom will use the maximum benefit of \$36,000 annually rather than the average of \$14,000 (??) now used by MA and PH-95 clients.¹⁴⁰
- ❑ The Insurance Federation of Pennsylvania (IFP) notes that there will be “very little” increase in appropriate use.¹⁴¹

Proponents of HB 1150 agree that the mandate would increase appropriate use. The “appropriate” use of treatment services hinges on the adequacy of diagnosis, care plans, covered services, provider competencies, medical necessity and effective practices among other factors. Pennsylvania’s family advocates and health insurers alike argue that access to and receipt of current DPW services are not adequate. Families cite out of pocket expenses for additional ABA sessions and other costs, to which there is certainly a limit. Evidence from the literature, cited earlier in this Review, indicates that individuals with ASD, in the absence of coverage for early behavioral interventions, will consume high levels of outpatient, psychiatric inpatient and pharmacy benefits that are clearly not the most effective services to treat ASD, but may be the only covered services available to that individual under a family’s health insurance policy. In fact, some individuals may not learn from their practitioners about “appropriate” services, if these are not covered. A national survey of physicians revealed that as many as 31% sometimes failed to offer “useful services” to patients if they perceived that those would not be covered by insurance.¹⁴²

Given the current constraints to appropriate use of effective treatment services for ASD, the proposed benefit will increase the use of these services. The composition of the ASD benefit and the required DPW regulatory activities outlined in the HB 1150 legislation comprise a set of strategies to ensure appropriate use of treatment services. According to the evidence submitted detailing DPW activities pursuant to the Autism Task Force, a number of strategies are already being pursued, including:

- ❑ Diagnostic Evaluation and Treatment standards setting
- ❑ Training of primary care doctors to early identify signs of ASD

¹⁴⁰ Blue Cross of North Eastern Pennsylvania Letter of 10-04-07 from Kimberly Kockler to Flossie Wolf at PHC4

¹⁴¹ Insurance Federation of Pennsylvania Letter of 10-04-07 from John Doubman to Flossie Wolf at PHC4

¹⁴² Wynia MK, VanGeest JB, Cummins DS, Wilson IB. Do Physicians not offer useful services because of coverage restrictions? *Health Affairs* 2003;22(4):190-197.

- ❑ Increase numbers of and train credentialed physicians and psychologists to perform standardized diagnostic evaluations to improve access and appropriate use of care
- ❑ Training of credentialed providers to develop appropriate plans of care, incorporating evidence based practices, including ABA
- ❑ Training of providers to implement ABA services¹⁴³

HB 1150 provides further direction to DPW to:

- ❑ Define medical necessity and identify evidence based treatment practices
- ❑ Set standards for practitioners for credentialed participation in private insurance provider networks to improve access to trained clinicians and appropriate treatment
- ❑ Address out of pocket expense barriers for families who will use the mandated benefit, by wrapping PH-95 coverage around the families for those expenses¹⁴⁴

While these steps will increase the appropriate use of treatment, they may also serve to ensure that the services used will have the best result. As cited earlier in this Panel Report in answer to Question 3, there is “good evidence of the cost-effectiveness of expanding IBI to cover all children within a defined administrative area (Ontario, Canada).” Moreover, the emphasis on making evidence based services accessible and affordable, combined with training on practice and care plan standards can have the effect of shifting services utilization away from those psychiatric treatments that are costly and ineffective in meeting appropriately the needs of persons with ASD. Utilization shifts can also serve to limit any cost impacts associated with increases in the appropriate use of treatment. Finally, the plans can implement provider training and care management practices that will promote services utilization shifts and impact costs.

D. Impact of the benefits on administrative expenses of health care insurers

Pennsylvania insurers cited, in their submission, increases in administrative costs pursuant to implementation of the ASD mandated benefit. In particular two companies listed estimated cost increases:

- ❑ \$9M from Highmark on a total estimated premium increase of \$81.5M, which represents 11% of premium costs
- ❑ \$500K from BCNEPA on a total estimated premium increase of \$12M, which represents 4.1% of premium costs

¹⁴³ DPW Bureau of Autism Services Update, PowerPoint Presentation, April 3, 2007

¹⁴⁴ Autism Spectrum Disorders Coverage, H. 1150, The General Assembly of Pennsylvania, Session of 2007. Amendment to Pennsylvania Code P.L. 682, No. 284. The Insurance Company Law of 1921, May 17, 1921.

It is difficult to determine the basis of these estimates without knowing the cost assumptions on which these amounts were based. One article submitted to PHC4 cited 12% of total premium costs as the typical administrative cost portion.¹⁴⁵ Taking its estimate from Pennsylvania insurers' previous filings to PHC4 (NOTE: the referenced documents were filed by the insurers and are not the analysis of the PHC4 staff), Boudier's analysis for the Vista Foundation estimated administrative expenses at 10% of total premiums.¹⁴⁶ A better assessment could be made with further delineation of the cost elements contained in those insurers' administrative expense. Typically, administrative expense cost elements include:

- ❑ Filing riders and updating contracts to include new benefits
- ❑ Eligibility determination and enrollment, although most target MA and PH-95 clients are already enrolled through their families
- ❑ Member services – while the privately insured families are not new members, they may seek assistance from member services in the first year of the mandated ASD benefit to determine how to use the new benefit
- ❑ Utilization and care management – these activities may actually decrease medical costs
- ❑ Network management – DPW will set and apply standards, focus on recruitment and share its current network, saving the private insurers on many of the recruitment and credentialing costs
- ❑ Claims payment and adjudication – Information systems will require one time modification to pay claims properly for new services, but services substitution may limit the net number of new claims and claims for these benefits should not be any more expensive to process than those for other medical services

There does not appear to be any disagreement between opponents and proponents in estimating the percent of administrative costs.

E. Impact of the proposed benefits on the benefits costs of purchasers

Evidence from opponents of HB 1150 includes:

- ❑ Highmark estimates \$81.5M in increased premium costs on a customer base of 4.1M

¹⁴⁵ Lemieux, J. "Perspective: Administrative Costs of Private Health Insurance Plans. AHIP Center for Policy and Research, Date..."

¹⁴⁶ Boudier, JN. In Response to the Notice in re Mandated Benefits Pertaining to HB 1150 of 2007. Vista Foundation 2007; pp. 1-17 and Exhibits A-E.

- ❑ IBC estimates \$57M in increased premium costs based on a treated prevalence assumption of 1 in 400
- ❑ BCNEPA estimates \$12M (\$11.5 M medical and \$500K administrative) in increased premium costs on a customer base of 600K, with a treated prevalence assumption of 1 in 150, each of whom will use the maximum of \$36K per annum
- ❑ The Chamber of Business and Industry cites 4% as a “conservative estimate pf premium increases on 16,000 contracts serviced by its PCI subsidiary, where the average monthly premiums equal \$550, and the premium increase is estimated at \$264 per year or \$22 per month per contract employee
- ❑ The Insurance Federation of Pennsylvania cites estimates of actuaries at between 2 and 6%

Absent consistent information on each plan’s current premium base, as well as treated prevalence and average benefit expenditures, it is difficult to compare these submissions or to draw conclusions about their accuracy or fairness.

Evidence from proponents of HB 1150 contained more detailed cost analyses. Proponents submitted many of the studies of other states’ mandates that are outlined in Section B, above in answer to the sub-question on the impact of similar mandates on costs. The Vista Foundation conducted an analysis for the proponents along the lines of those typically conducted by actuaries, employing current Pennsylvania epidemiological, coverage and cost experience. Proponents’ major findings on cost impacts include:

- ❑ Fuhr and Stefanacci
- ❑ The Department of Defense (DOD) published a Report examining autism mandates in numerous jurisdictions across the county where the DOD had covered lives in its TriCare insurance program, concluding that premium increases would be in the range of 1%¹⁴⁷
- ❑ A study by the opponents of South Carolina’s autism mandate, which has a higher cap than Pennsylvania of \$50K per child per year, finds the increase to be \$48 per member per year, or \$4 per member per month (pm/pm) and just under 1% of current premiums
- ❑ In Wisconsin, which has no cap, analyses of the mandated benefit review premium increases of \$3.45 to \$4.10 pm/pm
- ❑ A study by the New Jersey Mandated Benefits Advisory Commission, reported in 2006, evaluated the impact of the ASD mandated benefit contained in Assembly Bill A-999, finding that the cost impact on a family health insurance policy was approximately \$10.17 per month, or approximately 1% of premium¹⁴⁸

¹⁴⁷ Department of Defense Report and Plan for Services to Military Dependent Children with Autism, 2007.

¹⁴⁸ New Jersey Mandated Health Benefits Advisory Commission. A study of Assembly Bill A-999. Available at http://nj.gov/dobi/mhbac/070314_A999rpt_MHBAC.pdf

- ❑ According the Kaiser Family Foundation (KFF) average costs in 2007 for group family health insurance coverage in the United States was \$1,008 per month¹⁴⁹
- ❑ The Vista Foundation employed the KFF 2007 average family health insurance policy costs to its analysis of cost impacts for HB 1150

PA insurers have not provided evidence of the analyses that would support the levels of cost increase that are cited in the correspondence from several plans. Vista Foundation's analysis is the most comprehensive submitted and follows the guidelines of the American Academy of Actuaries¹⁵⁰, which include the following components:

- ❑ Size of risk pool:
 - employing Pennsylvania epidemiological data from 2000 to determine the total eligible population of 3,419,801 individuals, ages 0 to 20,
 - noting that insurers/IFP estimate that only 42% are covered in non-ERISA plans and 8.3% are uninsured, so that the real eligible population is between 1,317,102 and 1,363,064,
 - of which the total risk pool of potential beneficiaries who have ASD is between 8,781 and 9,087 children,
 - with the likely user pool of 1 in 500 estimated at between 2,634 and 2,726 children who will likely be treated,¹⁵¹ based on examination of several studies that respectively found treated prevalence for autism services between 1 in 520.83¹⁵², 1 in 476.19¹⁵³, and 1 in 500¹⁵⁴
- ❑ Case Mix: with the numbers cited above, the mix of autism cases among all cases is known, however, data are not available from the Commonwealth or the private insurers on the mix of need, diagnostic and/or functional subgroups within the universe of potential beneficiaries or the treated population
- ❑ Intent of purchaser cohort: Since Pennsylvania insurers' pools were prior established for employment purposes other than buying insurance, and more

¹⁴⁹ Health insurance premiums rise 6.1 percent in 2007, less rapidly than in recent years but still faster than wages and inflation. Kaiser Family Foundation. September 11, 2007. Available at <http://www.kff.org/insurance/ehbs091107nr.cfm>.

¹⁵⁰ Uccello, Senior Health Fellow, American Academy of Actuaries, NCSL 2007

¹⁵¹ Boudier, JN. In Response to the Notice in re Mandated Benefits Pertaining to HB 1150 of 2007. Vista Foundation 2007; pp. 1-17 and Exhibits A-E.

¹⁵² Leslie and Martin (p. 352); Leslie DL, Martin A. Health care expenditures associated with autism spectrum disorders. Archives of Pediatrics and Adolescent Medicine. 2007; 161:350-355.

¹⁵³ Liptak et al (p.872); Liptak GS, Stuart T, Auinger P. Health care utilization and expenditures for children with autism: Data from U.S. national samples. Journal of Autism and Developmental Disorders. 2006; 36:871-879.

¹⁵⁴ Mandell et al (p. 477); Mandell DS, Morales KH, Marcus SC, Stahmer AC, Doshi J, Polsky DE. Psychotropic medication use among Medicaid-enrolled children with autism spectrum disorders. Pediatrics. 2008; 121:e441-e448.

particularly, this ASD benefit, the PA insurers are less subject to adverse selection and the mandate will put no company at a particular disadvantage. While some individuals may enter the market because of the mandate, it is unlikely to have a substantial impact since PA already wraps medical around its own purchases of private insurance for children meeting certain means and insurance tests.

- ❑ Mandated coverage effects: mandated coverage will minimize the effects of adverse selection that derives from unique knowledge of particular health conditions or insurance benefits, although all agree that small businesses who are less likely to be self-insured due to smaller risk pools, are also less likely to be ERISA exempt and therefore disproportionately subject to the mandate as compared to larger businesses
- ❑ Measures of prior health spending: the Vista Foundation analysis employs measures of prior health spending in three scenarios it analyzes – the Commonwealth’s MA Fee-for- Service experience of \$11,500 average annual cost, and a research study by Chasson et al. of EIBI reporting a \$22,000 average annual cost, and the Pennsylvania private insurers maximum estimate of \$36,000 for the third scenario
- ❑ Trend data for estimates of future costs: Vista employs the future cost adjustment rates outlined in the ASD mandate
- ❑ Administrative cost data: Vista uses the historical rates of 10% filed with PHC4

F. Impact of the proposed benefits on the total cost of health care within the Commonwealth

Submissions to PHC4 have addressed the major areas required to determine the impact of the proposed benefits on the total cost of health care in the Commonwealth. While detail to support some of the cost estimates is lacking in the presentations by Pennsylvania insurers, considerable detail is provided by proponents in the areas required by PHC4, including:

- ❑ Baseline number of individuals who might utilize benefits
- ❑ Baseline coverage, estimated costs of that coverage and utilization costs that can be translated into PM/PM expenditures
- ❑ Projected utilization anticipated under specific provisions of the HB 1150
- ❑ Projected marginal impacts on premiums and out of pocket expenses
- ❑ Impact that increased coverage would have on utilization driven health care costs
- ❑ Longer term estimates of cost savings and medical cost offsets

Summaries of the findings on these factors are outlined in Sections A through E of Question 8. Taken together, these forecast:

- ❑ a number of potential beneficiaries, to which all parties agree

- ❑ a relatively low treated prevalence, to which proponents and several private insurers agree
- ❑ agreement on administrative costs
- ❑ utilization and average cost estimates from baseline costs under MA and PH-95 programs, which need to be adjusted for those individuals who are privately insured but do not meet the PH-95 disability criteria
- ❑ marginal premium impacts of up to 1% for mandate implementation under several defined scenarios/sensitivity analyses according to the detailed analyses provided by the Vista Foundation and consistent with the 1% figure cited in studies from the Department of Defense and other state jurisdictions evaluating ASD mandates
- ❑ some private insurers project marginal premium impacts of 4% , based on assumptions that all children with an ASD diagnosis (total population prevalence as opposed to treated prevalence) will use the maximum (\$36,000 per annum), although the supporting analyses were not submitted for review
- ❑ potential medical cost offset in outpatient, inpatient psychiatric and medication costs from application of behavioral therapies
- ❑ relief of out of pocket insurance expenses through continued availability of PH-95 coverage for those expenses
- ❑ projected reduction in family caregiver stress known to cause depression and other adverse health effects¹⁵⁵ and attendant savings in family health costs
- ❑ projected short term savings to the Commonwealth’s MA and PH-95 programs of \$22M¹⁵⁶
 - clinical effectiveness research studies provided indicate that improvements in clinical and role functioning and quality of life can be anticipated for those children and youth with ASD who use evidence based behavioral therapies, including Applied Behavioral Analysis.
- ❑ projected savings of \$187K to \$203K from age 3 to 22 and \$656K to \$1.1M from age 3 to 55 from EIBI treatment¹⁵⁷ on a lifetime \$3.2M per capita incremental costs of care for individuals with untreated ASD¹⁵⁸, with a strong foundation in

¹⁵⁵ Beresford, BA. “Resources and Strategies: How parents cope with the care of a disabled child.” *Journal of Clinical Psychology and Psychiatry*, 35,171: 1994

¹⁵⁶ Estimated fiscal impact of HB 1150 (PN #2237). Pennsylvania Department of Public Welfare 2007; Harrisburg, PA.

¹⁵⁷ Chasson GS, Harris GE, Neely WJ. Cost comparison of early intensive behavioral intervention and special education for children with autism. *Journal of Child and Family Studies*. 2007;16:401-413.

¹⁵⁸ Ganz ML. The lifetime distribution of the incremental societal costs of autism. *Archives of Pediatrics and Adolescent Medicine*. 2007;161:343-349.

the research literature, figures which in large measure represent avoidance of future state costs for adult care

In summary, the evidence submitted to the Pennsylvania Health Care Cost Containment Commission is sufficient to evaluate the impact of the HB 1150 mandate. The analyses and research papers support a finding of marginal premium increase costs of approximately \$1 PM/PM attributable to the ASD benefit. These cost increases are modest relative to: ongoing insurance cost increases; estimated cost offsets for families and the Commonwealth; and better results for children and youth with ASD. The clinical and cost effectiveness research studies provided indicate that improvements in clinical and role functioning and quality of life can be anticipated for those children and youth with ASD who use evidence based behavioral therapies, including Applied Behavioral Analysis.



Abt Associates Inc.

Appendix:

Autism Spectrum Disorders Mandated Benefits Review for
Pennsylvania House Bill 1150

Brief Panel Member Biosketches

Pennsylvania's Act 14 of 2003 specified five types of expertise to be included on Mandated Benefits Review Panels. These include: health research; biostatistics; economics research; insurance or actuarial research; and physician with experience in treating the target condition--in this case, autism spectrum disorders. The following sections provide brief descriptions of the backgrounds and experience of the members of the Autism Spectrum Disorders Mandated Benefits Review Panel.

Health Research

William E. Schlenger, Ph.D., Principal Scientist in Abt Associates' Behavioral Health Research Program, is a psychologist with broad interests and background in health, mental health and substance abuse research. Although best known for his contributions to the literature on the epidemiology of post-traumatic stress disorder (PTSD), his fundamental interest involves improving our understanding of the relationships among mental health, substance abuse and other behavioral and health problems. His career has centered on large-scale behavioral research studies conducted by multidisciplinary teams. Since 1990, for example, he has had senior leadership roles in the coordinating centers of eight major multisite collaboratives that studied psychosocial interventions aimed at treating or preventing mental health or substance abuse problems. These studies ranged from examinations of the efficacy of a broad range of community-based treatment interventions (e.g., mental health and substance abuse services for people with HIV infection, diversion from jail to mental health and substance abuse treatment for people with co-occurring disorders, improving the linkage of substance abuse treatment with primary care) to workplace-based preventive interventions (substance abuse prevention in managed care, substance abuse prevention aimed at young adults in the workplace).

Joseph P. Morrissey, Ph.D., is Professor of Health Policy & Administration and Psychiatry, at the Schools of Public Health and Medicine, and Deputy Director for Research, Cecil G. Sheps Center for Health Services Research, University of North Carolina at Chapel Hill. He served as principal investigator of a three-year (2001-2005) research grant from the NIMH to study the structure, utilization, and expenditures for services accessed by families on behalf of children with autism. He also was a co-investigator on a two-year (2004-05) autism services study funded by the Centers for Disease Control via the North Carolina Center for Autism and Developmental Disabilities Research and Epidemiology. The study assessed autism service use and expenditures over time in a cohort of 10 year olds as they moved from elementary to middle school. Currently he serves as principal investigator for a study funded by the NIH Office of Minority Affairs (2007-10) to develop and pilot test an advocacy intervention for African-American parents of children with psychological and behavioral deficits, including autism spectrum disorders.

Biostatistics

Lisa LaVange, PhD, is Professor and Director of the Collaborative Studies Coordinating Center (CSCC) in the Department of Biostatistics, School of Public Health, UNC-CH. Dr. LaVange joined the Biostatistics faculty in 2005, bringing extensive experience as a biostatistician in both pharmaceutical and government-sponsored research to the CSCC. She currently serves as Principle Investigator for the NHLBI sponsored Hispanic Community of

Health Study/Study of Latinos Coordinating Center, Principal Investigator of the Bronchiectasis Research Registry project funded by the COPD foundation, and co-Investigator for several clinical trials conducted as part of the NIMH sponsored Schizophrenia Trial Network. Prior to joining UNC, she was Vice President of Biostatistics and Data Management for Inspire Pharmaceuticals, Inc. and Vice President of Statistics for North American Clinical Development, Quintiles, Inc. Her industry experience spans drug development in the areas of cardiovascular, mental health, and respiratory disease. Prior to her industry experience, she worked for the Research Triangle Institute for 16 years where she was involved in a number of large scale national surveys, epidemiological studies, and clinical trials. Dr. LaVange is a Fellow of the American Statistical Association and served as President of the Eastern North American Region of the International Biometric Society (2007). She is associate editor of the Journal of Biopharmaceutical Research and editor of the ASA-SIAM book series. Her research areas include the design and analysis of clinical trials and complex sample surveys. She is currently co-instructor for two Biostatistics doctoral level courses, Clinical Trials and the Principles of Statistical Consulting.

Economics Research

Michael Ganz, Ph.D., is Associate Director of Outcomes Research in HERQuLES at Abt Bio-Pharma Solutions, Inc. Dr. Ganz' skills and experience are in health economics, program evaluation, and the analysis and management of health-related survey data. Prior to joining Abt Associates, Dr. Ganz was an Assistant Professor at the Harvard School of Public Health in the Department of Society, Human Development, and Health and currently serves as an Adjunct Assistant Professor at Harvard. Dr. Ganz has conducted publicly and privately funded research on health behavior decision-making as well as on the health care utilization and expenditures of special populations, including children with special health care need and has worked extensively with large representative national health surveys such as the Medical Expenditure Panel Survey and the National Health Interview Survey, as well as with health insurance claims. He has published on the epidemiology and utilization and expenditure patterns of a number of health conditions and special populations in leading journals such as the American Journal of Public Health, Health Economics, Ophthalmology, and Pediatrics. Dr. Ganz has a number of research interests including investigating the correlates and predictors of health care utilization and expenditures for children and families, especially for children with special health care needs (including mental health) and policy analysis and economic evaluations of the indirect effects of non-health policies on health. In 2006 Dr. Ganz published a chapter on the costs of autism and in 2007 he published a follow-up article in the Archives of Pediatrics and Adolescent Medicine that has been widely cited. Dr. Ganz has a PhD in Sociomedical Sciences and an MS in Biostatistics, both from Columbia University in New York, and a BS in Economics from UCLA.

Chris Pashos, Ph.D., is Vice President of Health Economic Research and Quality of Life Evaluation Services (HERQuLES) at Abt Bio-Pharma Solutions, Inc., a subsidiary of Abt Associates Inc. He joined Abt Associates in 1995 coming from the faculty of the Harvard Medical School. Dr. Pashos and his multi-disciplinary HERQuLES team collaborate internationally with clinicians, researchers and policymakers to assess the use, outcomes, and value of medicines, medical devices, biotechnology and other healthcare products and services. Having published in leading medical journals and lectured on the quality, cost and value of health

care, Dr. Pashos serves on the Editorial Advisory Board of the journal, Value in Health, and on the International Advisory Board of the journal, Current Medical Research and Opinion. He is a recipient of the Distinguished Service Award bestowed by the International Society for Pharmacoeconomics and Outcomes Research (ISPOR), and was elected to serve as President of ISPOR for 2008-2009.

Insurance or Actuarial Research

Danna Mauch, PhD, Principal Associate and Scientist in the Health Division at Abt Associates Inc., has more than 30 years of experience in designing, implementing and managing research, clinical and administrative services in the health arena. Dr. Mauch has extensive experience in the implementation and operation of specialty health plans, with a particular focus on co-occurring chronic health conditions, pharmacy and disease management, as the former CEO of Magellan Public Solutions, CAO of Comprehensive NeuroScience and President of Integrated Health Strategies. The focus of her work has also been on the integration of care systems, financing, and management information to support reforms and transformation of care for persons with complex behavioral and physical health conditions. Dr. Mauch consults with governments, corporations, and care systems involved in planning, financing, managing and evaluating health care services. Her clients include: HMOs, specialty care plans, and care management companies; state Medicaid, Medicare and public health programs; and CMS, HRSA, SAMHSA and the VA. She is experienced in managed care market analyses, strategic product management and operations readiness assessments. Dr. Mauch's recent work centers on the integration of systems of care, with particular emphasis on the financing, organization and management of care in the public sector, capitalizing on recent developments in evidence-based practices, Medicaid, Medicare and managed care reform.

Physician Experienced in Treating Autism Spectrum Disorders

Linmarie Sikich, MD, is a board certified child and adolescent psychiatrist who is an Associate Professor at the University of North Carolina at Chapel Hill, in Division TEACCH (Treatment and Education of Autistic and related other Communication-handicapped CHildren) and the Division of Child and Adolescent Psychiatry. She initiated the TEACCH Medical Consultation Clinic, whose goal is to facilitate the integration of biomedical, behavioral and educational treatments for individuals with autism spectrum disorders. She has also participated in several clinical trials for individuals with autism. Within the NIH-funded STAART (Studies to Advance Autism Research and Treatment) Psychopharmacology Network, she has played a leadership role and led an important study examining early psychopharmacologic intervention. She also has served as a reviewer of research proposals to: the MIND Institute, which strives to develop better treatments for neurodevelopmental disorders; Autism Speaks; and the National Institute of Mental Health