FUNDING BEHAVIOR-ANALYTIC AUTISM INTERVENTIONS: WHO PAYS?

Betsy Wurstner Swope

Temple University and The Devereux Community Adult Autism Partnership Program

Nina C. Wilde

Bucks County Intermediate Unit #22 and Temple University

James N. Bouder The Vista Foundation

Saul Axelrod Temple University

Philip N. Hineline Temple University

Abstract

Autism is often a devastating diagnosis for families to cope with and understand. In addition to the diagnosis and coping with the child's aberrant behavior, the limitations on funding for necessary behavioral interventions add even more stress for these families. Coupled with tight governmental funding, family financial constraints can make implementing home-based behavioranalytic programming difficult if not impossible. In recognition of this problem, Pennsylvania Act 62 of 2008 [originally House Bill (HB) 1150 of 2007], requires health insurance companies to cover up to \$36,000 yearly for behavioral and other clinical services until the age of 21. HB 1150 was opposed by insurance companies and business lobbyists, who argued that these services were adequately covered by the State Medicaid Plan, and they did not want to increase service costs for all members. Ultimately, policy makers passed HB 1150, securing "Pennsylvania's status as the national leader when it comes to helping families to deal with autism by ending discrimination in insurance coverage" (O'Brien, 2008).

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Currently, autism is expected to affect one in 150 children [Centers for Disease Control (CDC), 2006], and is the fastest growing developmental disability (Autism Society of America, 2008). With no cause or cure currently identified, professionals and parents are searching for effective intervention methods to ameliorate the deficits in language, communication and behavior commonly associated with this disorder. Research suggests that Applied Behavior Analysis (ABA) implemented in both home and school settings is the only empirically validated, effective method for intervention for children with autism (Howard, Sparkman, Cohen, Green, & Stanislaw, 2005; Rosenwasser & Axelrod, 2001). Although ABA has been established in the literature as an effective treatment for autism, it still can be a huge burden for families alone to undertake, both emotionally and financially. For this reason, it is important that other funding sources be identified to cover the cost of these treatments. Recently, through Act 62 of 2008, Pennsylvania enlisted the assistance of health insurance companies in covering these costs.

Applied Behavior Analysis as an Intervention Choice

Applied Behavior Analysis (ABA) is defined as "a scientific approach for discovering environmental variables that reliably influence socially significant behavior and for developing a technology of behavior change that takes practical advantage of those discoveries" (Cooper, Heron & Heward, 2007, pp. 3). ABA focuses on individual behavior and looks to improve human behavior through the scientific evaluation of data. Skills are taught in a highly structured environment through a process called shaping - the reinforcement of successive approximations of behaviors – until the new behavior is taught. During this time, data are carefully taken and evaluated to ensure the fastest rate of skill acquisition. Additionally, the functions of behavior including problematic behavior, such as tantrums, self-injury, and withdrawal, are examined and plans are developed to replace the challenging behavior with more functional, contextually appropriate behavior. By individualizing reinforcement and by teaching replacement skills, many problem behaviors can be reduced or eliminated and many new skills gained (The Vista School, 2008).

Historically, the application of behavior analysis to the treatment of children with autism developed with the work of O. Ivar Lovaas, who compared ABA treatment to less intense forms of treatment and to no special treatment. Results showed that ABA treatment garnered drastically better results than either of the other conditions (Lovaas, 1987), thus supporting ABA as efficacious in treating children with autism. Subsequent studies have also supported the use of intense ABA as a treatment for children with autism (e.g. Eldevik, Eikeseth, Jahr, & Smith, 2006; McEachin, 1993), and in a recent review article, Dawson (2008) summarizes the case that, with sufficiently early diagnosis, behavioral interventions show great promise for even *preventing* the development of autism in persons at risk, as well as providing remedy for those who have not benefited from the earliest diagnosis. Additionally, the recommendation of 40 hours per week of ABA programming as employed by

Lovaas's study has been cited by many parents as being vital to their child's success. The National Research Council's 2001 report summarizes the skills necessary for implementing an effective ABA program:

"Teachers must be familiar with theory and research concerning best practices for children with autistic spectrum disorders, including methods of applied behavior analysis, naturalistic learning, incidental teaching, assistive technology, socialization. communication. inclusion. adaptation of the environment, language interventions, assessment, and the effective use of data collection systems. Specific problems in generalization and maintenance of behaviors also affect the need for training in methods of teaching children with autistic spectrum disorders. The wide range of IQ scores and verbal skills associated with autistic spectrum disorders, from profound mental retardation and severe language impairments to superior intelligence, make the need for training of personnel even greater." (p. 184)

When considering the intensity and expertise required to carry out ABA programs similar to those in Lovaas's study as well as in other studies demonstrating the effectiveness of this approach, the burdens of implementing ABA in the home setting start to become clear.

Families and In-Home ABA Programming

When setting up ABA programs in the home, parents are typically responsible for choosing the direction of programming, in addition to hiring and training instructors, organizing the intervention schedule and finding funding for the entire process. Besides these tasks, many families are heartbroken by the diagnosis alone and may be unable to take action. A mother of a child with autism, Kathy Biernat, recounts her struggle with learning her son's diagnosis and grappling to set up a home program intervention (Biernat, 2000). In addition to the "head-spinning" associated with receiving the diagnosis and only weeks later attempting to set up a program, she also described being "bombarded with therapists in [her] home more than 30 hours a week" (Biernat, pp. 207). This is characteristic of many families' experience, because ABA programs often require at least two or three instructors to accomplish 30 to 40 hours of treatment per week.

Besides the revolving door of instructors, there is increased stress for families who are heavily involved with operating an ABA program (Schwichtenberg & Poehlmann, 2007). This aligns with Biernat's descriptions of stress in handling the situation with her son with autism, especially if she was heavily involved in the programming. On the other hand, Schwichtenberg and Poehlmann suggest that ABA can be a great resource for families with autism, noting that families actually experienced fewer depressive symptoms when children spent more hours in ABA programs; however, as mothers became more involved in this programming, the personal strain on them very much increased. These authors suggest that these findings indicate that mothers, especially, should not be the sole instructional coordinators for programming. Hastings and Symes (200) propose that if parents are trained as instructors and are under stress from running an ABA program, this can impact their instructional performance and may be detrimental to the child's program. Program developers need to recognize the demands that these arrangements place upon families, and provide additional supports (Hastings & Symes).

While the burdens of ABA programming can have detrimental side effects, assuming these responsibilities themselves often is the only way that a family can mitigate the huge financial costs of in-home programs. If they do not take on the roles of instructors and program organizers, parents must find a service provider, which can cost tens of thousands of dollars per year. Mulick (1999) estimates that the cost to families to provide in home ABA programming can range from \$30,000 to \$60,000 per year, which for many parents amounts to at least one, if not two, incomes. Sharpe and Baker (2007) interviewed families to assess the financial strain associated with having a child with autism. One family reported that they had "cashed out [a] 401k from [their] former employer... Have sold all [their] stock... Taken out an equity line of credit on [their] house to pay for therapies" (Sharpe & Baker, pp. 259). As evidenced in these testimonials, the financial burdens at times become so great that many families are forced into bankruptcy (Sharpe & Baker).

Not only do families with children with autism suffer financially from their expenditures on services, research also suggests that they may lose household income as byproduct of having a child with autism (Montes & Halterman, 2008). Specifically, Montes and Halterman found that families with a child with an autism spectrum disorder (ASD) lose an average of 14%, or about \$6,200 of income. Montes and Halterman suggest that this may be primarily due to the fact that parents of children with autism must make different working choices than other parents, such as working part-time instead of full-time. Additionally, they purport that families having a child with autism have less savings and investments because of the expenses for their child with autism. This lack of savings may relate to the increased medical expenditures faced by families of children with autism (Autism Spectrum Disorders Mandated Benefits Review Panel Report: Evidence Submitted Concerning Pennsylvania HB 1150, 2008).

Despite the drawbacks of associated stress and financial strain, ABA programs can offer families a sense of empowerment against autism (Dillenburger, Keenan, Gallagher, & McElhinney, 2002). Dillenburger et al. studied families who were running ABA programs and found that these programs can also have positive impacts on families. Through the use of ABA, parents have gained more structure in their family life, thus allowing them to go on more family outings and have increased feelings of control over the familial situation (Dillenburger et al.).

As noted above, ABA has been shown to be efficacious, and participating children make substantial long-term gains. Additionally, research suggests that families who participate in ABA experience less depression, increased selfesteem and feel more empowered (Dillenburger, Keenan, Gallagher, & McElhinney, 2002; Schwichtenberg & Poehlmann, 2007). However, the burdens, mostly financial, associated with the programs make it difficult for families to undertake them at home. This leaves difficult choices for families and policy makers alike. Who then should pay for these programs – school districts and the state government, private insurance agencies or some other entity?

Public Funding for ABA Programs

In looking at school districts and the state governments, it is important to offer some background on the sometimes rocky relationship already established between families and these organizations. The resources needed to serve children with autism significantly exceed the resources required for other students with special needs. The United States Government Accountability Office cited a report (GAO-05-220) by the National Research Council stating that the average annual cost for educating a typically developing student in public education was \$6,500 in 2001, and was \$12,500 for a special education student. Additionally, the average annual education cost for a student with autism in 2001 was \$19,000, with 43% spent on special education classes (teachers, instructional assistants), 24% spent on related services such as speech, occupational therapy, physical therapy, behavior analyst, or psychologist, 19% spent on resource services, and 14% spent on other services. These services are paid for by taxpayers through support of the public schools, Medicaid, home- and community-based service waivers, and lastly private insurance (United States Government Accountability Office). Additionally, there continues to be a need for services delivered in the home setting, for the public schools cannot, alone, bear the full burden of comprehensive autism interventions. Zirkel (2002) reported a steady increase in the numbers of parents and school districts going to court over autism services. Many of these cases have dealt with in-school programming and implementation; in addition many parents advocate inclusion of intervention in the home-setting as part of the school district programming for students with ASD (Choutka, Doloughtry, & Zirkel, 2004). Interestingly, findings suggest that neither the school district nor families consistently win in court cases involving children with autism (Choutka et al). Whoever wins, current solutions typically do not fill the gaps and the fact remains that other sources of funding need to be examined in order to ease the tension between the school districts and families.

The Medical Assistance system in Pennsylvania is already overburdened, so this, too, cannot be a long-term, viable option for providing all services for many children with autism. Administrators of these programs in the Department of Public Welfare acknowledge that their services do not address the life-long needs of individuals with autism, but instead operate as if autism were a short-term medical condition. They also acknowledge the need to individualize care for each child. However, their system was originally designed for people with mental retardation or mental illness (Autism Spectrum Disorders Mandated Benefits Review Panel Report: Evidence Submitted Concerning Pennsylvania HB 1150, 2008). Additionally, the requirements and re-evaluations to maintain funding have been viewed by parents to be "medically unnecessary, needlessly intrusive, and demeaning" (Autism Spectrum Disorders Mandated Benefits Review Panel Report: Evidence Submitted Concerning Pennsylvania HB 1150, pp. 5). Although these are just a few of the cited gaps between the services of Medical Assistance and the needs of children with autism, it is clear that this system, operating on funds that are not necessarily guaranteed to exist in the near future (Autism Spectrum Disorders Mandated Benefits Review Panel Report: Evidence Submitted Concerning Pennsylvania HB 1150), cannot provide these services alone.

ABA As a Cost-Effective Option

Recently, in response to the need for expanded clinical and in-home ABA programming for children with autism and the lack of funding available for these programs, the state of Pennsylvania proposed HB 1150. This bill stated that insurance companies would be required to provide up to \$36,000 annually for the diagnosis and treatment of autism, including ABA intervention until age 21. It was imperative for proponents of HB 1150 to demonstrate that ABA treatment was a cost-effective treatment for children with autism. However, when considering available research on a cost-benefit analysis of ABA, the amount of research is surprisingly small, given how effective ABA programming has been in treating this disorder

Jacobson, Mulick, and Green (1998) examined the cost-effectiveness of ABA programs using statistics from Pennsylvania in a cost-benefit model. This model took into account various success rates for individuals in ABA programs. Even while considering the likelihood that not all children will graduate into general education classrooms even after ABA treatment, they suggest an average savings between \$187,000 to \$203,000 per child for ages 3-22 years and \$656,000 to \$1,082,000 per person for ages 3-55 years (Jacobson, Mulick, and Green). Therefore, the up-front costs required to fund these programs (approximately \$30,000-\$60,000 per year, per child for a very few years) pale in comparison to the savings realized over a lifetime.

Further support for this finding comes from Chasson, Harris, and Neely (2007), who performed a similar analysis in the State of Texas. They found that after three years of early intensive behavioral intervention, the state could save, on average, \$84,300 per child in special education costs. Combined with actual costs incurred by families, this could result in savings of \$208,500 per child. They also suggest that the up-front costs of providing ABA programs are recovered within five years. Although compelling, this difference may not be compelling enough evidence for many school districts to accept the burden of providing these up-front funds alone. A distinction between state savings and the savings accruing to the actual school district needs to be recognized when considering this cost-effective argument. Additionally, Chasson et al. suggest that the heterogeneity of the population of children served by special education school programs may contribute to their lack of effectiveness. Children with autism are only a sector of the special education population, and ABA services must be tailored to meet the needs of each individual child. Therefore they suggest that "it would behoove policy makers to reconsider the role of educational services with children with developmental disabilities. Indeed, it may mean a minimization of the education system's role in providing services and a maximization of population-specific treatment implementation by mental health practitioners. Following from this, special education would then have expanded resources to serve children who failed to mainstream into typical education despite implementation of appropriate interventions" (Chasson et al., pp. 401). If ABA is to be a cost-effective intervention, the benefits must be realized by all stakeholders – by parents, by local, state and federal agencies, by insurers, and by the public at large.

Ganz (2007) examined the societal costs of autism in the United States that will be incurred if children with autism do not participate in effective interventions and do not become contributing members of society. By reviewing information on medical care costs across a typical lifespan, in addition to lost wages because these individuals were not able to work and contribute to society, Ganz estimates the cost of caring for an individual with autism across the lifetime to be about \$3.2 million. He notes that adult care is the largest direct cost over the course of the lifetime, which ends up being five times larger than the next three largest costs – behavioral interventions, child/respite care, and special education (Ganz). Interestingly, these three costs are all associated with childhood. Thus, if the cost is expended during childhood, the high cost associated with adult care can potentially be avoided.

Studies supporting behavioral interventions as cost effective do not come without their critics, however. Marcus, Rubin, and Rubin (2000) suggest that the authors should not assume that ABA is the only treatment that would be cost-effective, because the studies substantiating ABA as an effective treatment possess methodological flaws. One of the biggest problems the authors highlight is the lack of replication of the results found by Lovaas (1987). Since the publication of Marcus et al., Sallows and Graupner (2005) replicated the findings of Lovaas (1987) and supported the use of ABA. Additionally, Marcus et al. point out that "there has not been (and may never be) a comprehensive comparison study of different intervention approaches" (pp. 595), thus, other treatments may be as cost-effective as ABA. A recent, comprehensive synthesis of early intensive behavioral interventions by Reichow and Wolery (2008) addressed such cautions while, including descriptive analyses, effect-size analyses, and a meta analysis that systematically integrated the results of multiple studies. While emphasizing the need for further research, these "The findings suggest Early Intensive Behavioral authors concluded: Intervention is an effective treatment, on average, for children with autism." Supporting cautions of a different kind, Howard et al. (2005) published research suggesting that other types of eclectic treatments for autism are not as effective for treating autism as ABA. Additionally, at least seven nationally recognized entities – The U.S. Surgeon General's Report on Mental Health, The New York Department of Health, the Maine Administrators of Services for Children with Disabilities, The National Institute of Mental Health, The National Institute of Child Health and Human Development, The National Research Council and The Association for Science in Autism Treatment support ABA as a treatment of choice for autism (Autism Speaks, 2007).

Insurance Companies as a Funding Source for ABA Treatment

In reviewing the existing cost information that identifies the benefits of an empirically validated program such as ABA, and knowing that autism is a psychological disorder causing families great stress, it appears logical that insurance companies should pay for ABA intervention. In a recent report released by the Pennsylvania Health Care Cost Containment Council, reviewers suggested that health insurance companies should be accountable for coverage of autism intervention (Autism Spectrum Disorders Mandated Benefits Review Panel Report: Evidence Submitted Concerning Pennsylvania HB 1150, 2008). However, many insurance companies wrote exclusions for coverage for those diagnosed with autism. This prohibited families from receiving coverage for their child with autism which included ABA treatment. Within Pennsylvania, insurance reform to include autism and ABA was resisted by some insurance companies. Insurance companies opposed HB 1150 for two primary reasons – the already existing coverage by Medical Assistance for these programs and projected increases in private insurance premiums (Bouder, 2007).

Insurance companies argued that Medical Assistance should already cover these areas, despite identified gaps such as sub-par services resulting in slow progress or programs stopped due to "lack of progress" (Bouder, 2007, pp. 4). Insurance companies suggested that passing these gaps on to them would only exacerbate the problem. Insurance companies asserted that they have no experience in organizing groups of developmental disability providers and cannot be expected to ameliorate these problems (Autism Spectrum Disorders Mandated Benefits Review Panel Report: Evidence Submitted Concerning Pennsylvania HB 1150, 2008). However, the insurance industry has experience with networking providers of other services, so lack of this particular experience should not be an excuse for an inability to cover services. It surely is feasible that this experience could carry over in the designing of new systems for developmental disabilities. Bouder made an interesting point when considering this support. He noted that "if these services were already covered by Medicaid, or the services provided met published standards, why would parents devote so much of their already heavily tapped resources to advocate so strongly and in such large scale for an end to the diagnostic exclusion of Autism Spectrum Disorders?" (Bouder, pp. 8).

Evidence strongly suggests that the rate increase estimates provided by the insurance companies overstated the likely rate increase attributable to HB 1150 when enacted. The Insurance Federation of Pennsylvania estimated an impact of a 2% to 6% increase. The Pennsylvania Chamber of Commerce estimated at different times a health insurance premium impact of 4% to 8%. Additionally, a Highmark executive at a regional Chamber of Commerce meeting stated an 11% increase could occur under HB 1150 (Bouder, 2008). When evaluating the rate increase, important assumptions about prevalence rate and utilization need to be made. Based on actuarial estimates provided by proponents of HB 1150, an 11% increase would require the prevalence rate of autism to be one in 31 children, which is much higher than current rate of one in 150 or an annual cap far greater than \$36,000 annually (Bouder). In reality, given the current prevalence, utilization and monetary cap rates, the actual rate increase is significantly less than 1%, or about \$1.28 to \$2.62 per member per month (pmpm) for single-policy rate and \$3.56 to \$7.23 pmpm for family rates (Bouder). Even in the highly unlikely event of every child and youth below the age of 21 who meets the diagnostic criteria for an Autism Spectrum Disorder utilizes the benefit to the full \$36,000 annual sum, the greatest possible average effect on premiums would be approximately 2.31% (Bouder). The Independent Review Panel engaged by the Health Care Cost Containment Council pointed out that this analysis by Bouder and the Vista Foundation was the most comprehensive, and that it followed the guidelines of the American Academy of Actuaries (Autism Spectrum Disorders Mandated Benefits Review Panel Report: Evidence Submitted Concerning Pennsylvania HB 1150). Ultimately the Health Care Cost Containment Council report estimated the likely rate impact to be less than 1%, or approximately \$1 per member per month (Autism Spectrum Disorders Mandated Benefits Review Panel Report: Evidence Submitted Concerning Pennsylvania HB 1150, pp. 51). In comparing this small monthly increase to the \$13 billion to \$76 billion spent by society over the lifetime of this cohort of children with autism (Ganz, 2007), the annual cost appears well justified.

In addition to supporting a minimal rate increase, the Health Care Cost Containment Council report also commended the proponents of HB 1150 for successfully demonstrating that ABA intervention is an evidence-based practice according to the standards of the Blue Cross Blue Shield Association (BCBSA) – the standards of an opposing party. Autism Spectrum Disorders Mandated Benefits Review Panel Report: Evidence Submitted Concerning Pennsylvania HB 1150 (2008) stated that proponents submitted "volumes of testimony, research papers and data analyses. In contrast, the opponents submitted fewer than a dozen letters" (pp. 35). Ultimately, the opponents of HB 1150 offered no compelling scientific, economic or public policy reasons for permitting the continued diagnostic exclusion practices toward children and youth with autism. In contrast, proponents demonstrated the soundness on all three bases, even up to the industry's own standards for making science-based coverage decisions.

Conclusion

The authors of this paper believe it is very difficult to convince members of society that current expenditures for expensive interventions will pay off later on, when these children become adults. Often times, the money for interventions are provided from another entity's budget (i.e., state education funds are currently paying for many autism interventions, so there is less need for insurance companies to pay for these services). Additionally, for those families who are not personally affected by autism, these costs may appear unnecessary. For these reasons and many others, proponents of the bill faced multiple challenges in passing HB 1150.

Although the bill was originally passed unanimously by the Pennsylvania House of Representatives in 2007; when reviewed by the Pennsylvania Senate Banking and Insurance Committee in mid-2007, the bill was referred to the Pennsylvania Healthcare Cost Containment Council for a cost analysis (O'Brien, personal communication, September, 2007). Simply put, the State of Pennsylvania was questioning the cost-benefit of ABA when deciding if insurance companies should share the expense of ABA intervention for children with autism. With support and research submitted from many entities across the state, on June 19, 2008, the Healthcare Cost Containment Council released a report suggesting that HB 1150 would be beneficial to Pennsylvania and that the recommended treatments (i.e., ABA) would be cost-effective. This report cited and reviewed many of the studies referenced in the present paper, ultimately pointing out that there would be "marginal" premium increases of \$1 pmpm by implementing this coverage.

After further review and revision, including a new provision exempting small employers with 50 or fewer employees from the mandate, HB 1150 was passed in the Pennsylvania Senate on June 30, 2008 with a vote of 49-1 and was passed unanimously in the Pennsylvania House of Representatives on July 2, 2008. Pennsylvania Governor Rendell signed the strongest autism bill in the nation (Bouder, personal communication, 2008) on July 9, 2008 as Act 62 of 2008. The proponents of HB 1150, including Speaker O'Brien, Estelle Richman, Governor Rendell, and Senator Orie, in addition to the many other legislators, parents and advocates in the state of Pennsylvania should feel proud of the hard-work and dedication required to pass this bill, thus setting a national standard of excellence in autism insurance reform.

Although triumphant, the work on Act 62 is not over. Now passed, it will be important that swift action be taken to allow families to access this money and engage properly trained professionals to become providers of these services. The passage of Act 62 offers a momentous opportunity for all stakeholders – families, advocates, insurance companies, policy analysts in academic institutions, officials in the Department of Public Welfare and Health Care Cost Containment Council and other interested parties in the Commonwealth – to work collaboratively to gather and evaluate data based on the implementation of this noteworthy legislation. By tracking outcomes of children from families who receive insurance funding, further evidence can be provided regarding the necessity of any increases in premiums. Additionally, this will provide support for policy makers in other states who are confronted with this difficult funding issue.

Lastly, the exemption of small businesses from the coverage prescribed by Act 62, driven primarily by business and industry pressures and legislation enacted in other states, and not by evidence submitted to the Pennsylvania Health Care Cost Containment Council, raises questions concerning the effect the lack of access to this coverage might have upon small business owners and their employees. More study of both the cost impact of autism coverage on small businesses and the lack of coverage on the small businessperson is needed. By showing that insurance funding for behavioral programs leads to increased functioning and greater contributions to society, it is hoped that more states will be compelled to require insurance companies to fund these programs and allow families across America to receive the financial relief they deserve.

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