Annual Report
to the
Missouri Legislature

Insurance Coverage for Autism Treatment & Applied Behavior Analysis

Statistics Section
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DIFP

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Executive Summary

This is the third annual report to the Missouri General Assembly related to insurance coverage for autism treatment and applied behavioral analysis (ABA). The findings of the first annual report reflected the fact that 2011 was a transitional year during which much of the infrastructure necessary to deliver the mandated benefits was developed. As expected, data show that the benefits of the mandate were more fully realized in 2012 and on into 2013, while the costs as a percent of overall health care costs remained negligible.

1. **Coverage.** All insureds in the small and large group markets were covered for autism and ABA therapy by 2012. In both 2012 and 2013, a much lower proportion, less than one-third, received similar coverage in the individual market, including individually underwritten association coverage. A few large providers of individual insurance coverage extended autism / ABA coverage to all of their insureds. However, Missouri statute requires only an offer of autism and ABA benefits, and most insurers do not provide it as a standard coverage. For those insurers that do not provide the coverage as a standard benefit, only a negligible number of insureds purchased the optional autism rider.

2. **Number impacted.** The number of individuals receiving covered treatment in 2013 for an autism-related condition equaled 3,070, up from 2,508 in 2012. This amounts to 1 in every 431 insureds, up from 1 in 548 insureds in 2012. The ratio ranged from 1 / 1,312 in the individual market to 1 / 372 in the large group market. These figures are consistent with estimates in the scientific literature of treatment rates.[1]

3. **Licensure.** The first licenses for applied behavior analysis were issued in Missouri in December 2010. As of mid-January 2013, 218 licenses had been issued, and an additional 41 persons obtained assistant behavior analyst licenses. Of these, 181 behavior analyst licenses were still active, as were 23 assistant behavior analyst licenses.

4. **Claim payments.** Between 2011 and 2013, claim costs incurred for autism services increased from $4.3 million to $8.3 million, of which $3.8 million was directed to ABA services. These amounts represent 0.2 percent and 0.09 percent of total claims incurred, consistent with initial projections produced by the DIFP.[2] For each member month of autism coverage, total autism-related claims amounted to 48 cents, while the cost of ABA treatment amounted to 22 cents.

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[1] While the CDC estimates that the prevalence of autism is significantly higher than 1 in 372, autism presents with a high degree of variability. Not all such individuals will benefit from, or seek, treatment specifically targeted at autism.

[2] The DIFP estimated that the mandate would produce additional treatment costs of between 0.2 percent and 0.8 percent. The analytical assumptions associated with the lower-end of the estimate range appear to be validated by the claims data presented in this report.

5. **Average Monthly Cost of Treatment.** For each individual diagnosed with an autism spectrum disorder (ASD) who received treatment at some point during 2013, the average monthly cost of treatment across all market segments was $255, of which $118 consisted of ABA therapies. The average, of course, includes individuals with minimal treatment as well as individuals whose treatments very likely cost significantly more.

6. **Impact on Premiums.** While costs associated with autism-related treatment have risen over the prior two years, the fact that these costs represent just two-tenths of one percent of overall claim costs makes it very unlikely that they will have any appreciable impact on insurance premiums. However, because the DIFP has no authority over health insurance rates and does not receive rate filings, a more exact assessment of the impact of the mandate on rates cannot be provided.

7. **Self-Funded Plans.** This study focuses upon the licensed insurance market (i.e. those entities over which the DIFP has regulatory jurisdiction). Many employers provide health insurance by "self-insuring," that is, by paying claims from their own funds. Such plans are governed under the federal Employee Retirement Income Security Act (ERISA), and states have little jurisdiction over private employers that choose to self-fund. The Missouri statute does extend the autism mandate to the Missouri Consolidated Health Care Plan (MCHCP), which covers most state employees, as well as all self-funded local governments and self-insured school districts.

The advocacy group Autism Speaks maintains a list of self-funded private employers that have chosen to voluntarily provide coverage of autism and ABA therapy to their employees. Among this group are many of the most recognizable "high-tech" companies, including Microsoft, Intel, Adobe, Cisco, IBM, Apple, Yahoo and E-Bay. From the health care field are the Mayo Clinic and Abbott Laboratories. Additional companies come from a variety of sectors, from Home Depot to Wells Fargo. More recently, JP Morgan Chase & Co, GM, Chrysler, United Technologies Corp. and American Express have announced that they will begin offering the coverage. Because the DIFP lacks jurisdiction over private self-funded employers, the number of Missourians receiving autism benefits under private self-funded plans is unknown.

The DIFP encourages readers to check with their employer that may be self-insured to determine if coverage for autism treatments, including ABA, is included in their health benefit plan. Autism Speaks created a "Tool Kit" for employees of self-funded plans to approach their employers about adding benefits to their company health plan. The Self-Funded Employer Tool Kit can be found at http://www.autismspeaks.org/sites/default/files/docs/gr/erisa_tool_kit_9.12_0.pdf.

Introduction

House Bill 1311, signed into law by Governor Jay Nixon on June 10, 2010, mandated health insurance coverage for medically necessary treatment of autism spectrum disorders (ASDs). All group policies issued or renewed after January 1, 2011 were required to extend autism coverage to all insureds. All policies issued in the individual market were required to offer such coverage as an optional benefit for additional premium. In addition, the law required coverage for applied behavior analysis (ABA) for children up to 18 years of age. Required coverage for ABA was initially capped at $40,000 per year, to be annually adjusted. The annual cap for ABA therapy stands at $42,734 for 2014.

House Bill 1311 also directs the Department of Insurance, Financial Institutions and Professional Registration (DIFP) to assess the impact of the mandate on the health insurance market. This is the third annual report to the Missouri General Assembly.

Data were obtained from all insurers in the state with comprehensive health insurance in force and subject to the autism mandate. These data indicate that the mandate has succeeded in broadly extending coverage to autistic individuals. While overall claim costs for autism-related treatment increased by 92 percent between 2011 and 2013, autism-related claims amounted to just two-tenths of one percent (0.2 percent) of overall claim costs. Since claims are only one component of total costs that impact health insurance rates, the overall impact of the mandate on rates is likely to be significantly less than 0.2 percent.

History of HB 1311 and the ABA mandate

Prior to the passage of HB 1311 in 2010, Missouri law allowed exclusions in health insurance coverage for treatments that were considered primarily for familial, educational or training purposes; custodial in nature; not clinically appropriate; or that were experimental.

Autism treatments such as ABA were commonly excluded because they were considered experimental in nature. Prior analysis by the DIFP indicated insurance carriers did not offer benefits of a level or kind that could have been expected to have any significant impact on individuals diagnosed with an ASD. This analysis was consistent with the academic literature, which has documented that treatment for ASDs is either generally paid out-of-pocket by parents and relatives, provided via public services such as special education programs, or in some cases the condition is left largely untreated. Further, insurer-compensated treatment was not targeted to young individuals for whom treatments are known to be most effective and most likely to achieve an enduring and dramatic improvement in symptoms.

To address the inadequate coverage for the treatment of ASDs in the private insurance market, and to ensure broader access to treatments, HB 1311 established broad coverage requirements for ASD treatments. Applied behavior analysis (ABA) was mandated for individuals 18 and under, up to $40,000 per year (adjusted for inflation in each subsequent year). All group plans were required to provide coverage for all insureds. Individually underwritten health plans were required to extend an offer to cover the mandated benefits. In addition, HB 1311 established a system of licensure for behavioral analysts to ensure the delivery of high-quality care.

HB 1311 became effective for all health insurance plans issued or renewed in Missouri after January 1, 2011. Subsequently, 12 additional states enacted mandates similar to the Missouri law, including the requirement to cover ABA services. Another two states added the benefits to state employee health coverage. By mid-2013, 34 states and the District of Columbia had some form of mandate to cover autism.

To monitor the impact of HB 1311 on the health insurance market, the Missouri General Assembly included a requirement for the DIFP to collect data pertaining to the costs associated with the mandated benefits on an annual basis. The DIFP issued its first annual report on February 1, 2012. That report noted significant hurdles for the implementation of the new law: mandated coverage was not extended until the renewal date of a health insurance policy; therapists required training and credentialing to practice ABA therapy; providers faced infrastructure development to secure compensation for services that were previously excluded by most health insurance plans; and insureds faced a learning curve with respect to the scope of the newly available benefits. Data in both the 2012 report and the current report show that as the medical delivery infrastructure has become more firmly established, the benefits of the autism mandate were more fully realized.

Coverage

Percent of Member Months With Coverage for Mandated ASD Benefits By Market Segment 2013			
Market Segment	**Total Member Months**	**Member Months of Policies With Autism Coverage**	**% With Coverage**
Individual	3,307,538	1,081,217	32.7%
Small Group	5,247,180	5,247,143	100.0%
Large Group	10,995,801	10,995,801	100.0%
Total	**19,550,519**	**17,324,161**	**88.6%**

While all insureds in the group market received coverage for the treatment of autism, it appears that coverage in the individual market has not been broadly purchased by consumers, due to the cost of the optional coverage. For group coverage, costs associated with the mandate are borne by the entire group in the same manner as any other illness. Since only the offer of coverage is required in the individual market, there is a strong tendency toward "adverse selection" with respect to autism benefits. Namely, individuals selecting ASD coverage will be more likely to already have a dependent with an autism-related diagnosis. Since the coverage is usually provided as a rider at an additional premium, the entire costs of the mandated benefits are therefore concentrated among such policyholders. The resulting premiums likely make such coverage unaffordable for many. Based on consumer complaints received by the DIFP and other anecdotal evidence, the department is aware that the cost for an autism endorsement in the individual market can exceed $4,000 per month.

Eighteen carriers in the individual market reported extending autism coverage (including coverage for ABA) to all of their insureds beginning in 2012 – even though there was no legal requirement to do so. Correspondence with these carriers indicates that they determined that it was less costly to offer general coverage than to incur the additional expense of administering separate riders. For the remainder of carriers for which coverage is offered as an optional rider for additional premium, the take-up rate for ASD benefits is nearly zero. For these carriers, which comprise almost 70 percent of the individual market, only 2/100 of 1 percent (0.02%) of member months had such coverage in effect for 2013.

Coverage in the Individual Market – *Excluding* Insurers That Provide ABA Coverage to All Policyholders			
Member Months	**% of Individual Market**	**Member Months with Autism Coverage**	**% Member Months with Autism Coverage**
2,226,794	69.9%	473	0.02%

Beginning in 2014, federal law requires that all policies sold in the individual and small group market provide "Essential Health Benefits" (EHBs). Under current HHS regulations, the required EHBs are based, in part, on the coverage provided under the state's largest small group health plan, by enrollment. That plan would include all state mandated benefits applicable to the small group health insurance market. Thus, Missouri's autism mandate will apply to all non-grandfathered policies in the individual market beginning in 2014. For additional information on EHBs and their impact on insurance coverage of ASDs, please refer to the **Future Market Developments** section of this report.

Treatment Rates

The DIFP attempted to assess the prevalence of persons diagnosed with an ASD with coverage under a licensed health insurer. Unfortunately, insurers are only able to identify such individuals via information available from submitted claims, such that an individual with an ASD diagnosis must have sought a treatment for conditions specific to the ASD during the period under examination to appear in our data.[3] Thus, the estimates that follow should not be considered as even a proxy for ASD prevalence among those with health insurance coverage, but rather a subset of that group that received some form of ASD-related treatment during 2013. The overall prevalence of ASD-diagnosed insureds is quite likely to be significantly larger.

During the last year, over 1.3 million Missourians obtained comprehensive coverage through a licensed insurer[4] in the individual, small group or large group markets. Of this number, over 3,000 insureds sought treatment during the reporting period for which the primary diagnosis was an ASD. The majority of these individuals, or 2,165, were 18 and under and therefore eligible for coverage under the ABA mandate. Across all market segments, 1 insured in 431 sought treatment for an ASD-related condition. Treatment rates are considerably lower than the prevalence rate of ASDs in the general population, which the Centers for Disease Control has most recently estimated to be 1/88.[5] Autism can present with a high degree of variability. Many individuals with an ASD diagnosis will neither seek, nor benefit from, extensive treatment.

[3] That is, individuals that did not seek treatment directly associated with the ASD would not normally be identified on a typical claims form. The DIFP requested that insurers count anyone who sought an ASD-related treatment during the preceding 12 months as an insured with an ASD.

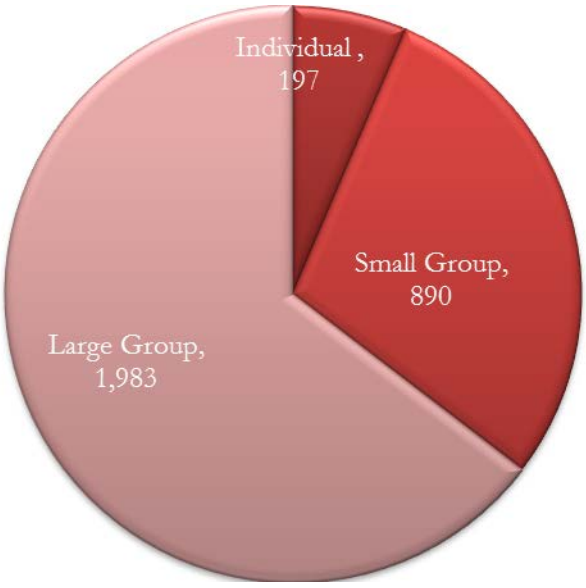
[4] These figures exclude plans that self-insure under federal ERISA statutes. Self-insurers comprise a significant portion of the group market. Prior estimates by the DIFP suggest that self-insureds represent as much as 2/3 of the group market. Also excluded from these figures are all forms of public coverage.

[5] More recently, the CDC issued an estimate of 1/50. However, the CDC cautions that because the 1/50 figure was based on a completely different methodology than the "official" estimate, it should be interpreted with caution. Namely, the 1/50 estimate was derived from a random survey of parents with school-aged children (6 to 17), while the 1 in 88 estimate is based on school and medical records of 8 year olds from the CDC's Autism and Developmental Disabilities Monitoring (ADDM) Network.

Prevalence of ASD Covered Treatment[6]				
Market Segment	**Insureds**	**Insureds With an ASD, Covered Under Mandate**	**1 Covered ASD Diagnosed Person Per X Insureds**	**Insureds Under 18 With an ASD**
Individual	257,871	197	1,312	164
Small Group	328,839	890	369	599
Large Group	737,673	1,983	372	1,402
Total	**1,324,383**	**3,070**	**431**	**2,165**

As expected, the percent of insureds identified as having an ASD was nearly twice as high in the group market compared to the individual market. Only 197 individuals sought treatment for an ASD in the individual market, representing about 6 percent of all such individuals across all market segments.

Insureds Treated for an ASD, by Market Segment



The total number of insureds receiving autism-related treatment in 2013 was slightly higher than in 2012, increasing from 2,508 to 3,070.

[6] Figures are based solely on initial survey responses of licensed insurers for fully-insured plans related to the data period 2013. Some entities that are known to offer autism-related benefits, such as the Missouri Consolidated Health Care Plan (MCHCP) and some self-insured employer plans, are not included in the data.

Claim Payments

During 2013, comprehensive health plans incurred over $4 billion in total claim costs. Only a small fraction of this amount resulted from autism-related treatments. Claims for all treatments related to autism amounted to $8.3 million, representing just two-tenths of one percent (0.2%) of total claim costs. Costs incurred for ABA therapies were only 0.09 percent of total claims, or $3.8 million.

Prior to the passage of the mandate, the DIFP estimated that the proposed legislation would produce claim costs of between 0.2 percent and 0.8 percent of total premium. Amounts incurred thus far are consistent with the lower end of the estimate.

Autism-Related Claim Costs in 2013			
Market Segment	**Total Incurred Losses**	**All Autism-Related Incurred Losses**	**Losses Incurred, ABA**
Individual	$548,453,281	$512,521	$256,682
Small Group	$1,110,253,261	$2,025,559	$1,258,191
Large Group	$2,547,814,804	$5,751,837	$2,314,637
Total	**$4,206,521,346**	**$8,289,917**	**$3,829,510**

Autism Treatment as Percent of Incurred Losses		
Market Segment	**All Autism-Related Incurred Losses**	**ABA-Related Incurred Losses**
Individual	0.09%	0.05%
Small Group	0.18%	0.11%
Large Group	0.23%	0.09%
Total	**0.20%**	**0.09%**

Between 2011 and 2013, claim costs incurred for autism-related treatments increased by 92.3 percent, from $4.3 million to $8.3 million. Most of the increase resulted from more intensive utilization of ABA therapies. Claim payments for ABA increased by 264.5 percent during the same period.

Payments for Autism-Related Treatments						
	2011	2012	2013	% Increase, 2011-2012	% Increase, 2012-2013	% Increase, 2011-2013
All Autism Costs	$4,310,010	$6,550,602	$8,289,917	52.0%	26.6%	92.3%
ABA	$1,050,764	$2,972,712	$3,829,510	182.9%	28.8%	264.5%
% ABA	**24.4%**	**45.4%**	**46.2%**			

Another method of expressing the costs of the mandate is the ratio of autism-related treatment costs to the total member months during which autism coverage was in effect. The resulting figure should afford a general indication of how monthly premiums might be expected to increase due to extending coverage for autism treatment. Across all market segments, the average autism-related claim costs for each month of autism coverage was $0.48, and $0.22 for the costs of ABA treatments.

Claim Costs for Autism Per Member Per Month for Policies with Autism Coverage in 2013					
Market Segment	Member Months of Policies With Autism Coverage	All Autism Related Claims	ABA Claims	All Autism-Related Claims, PMPM	ABA-Related Claims, PMPM
Individual	1,081,217	$512,521	$256,682	$0.47	$0.24
Small Group	5,247,143	$2,025,559	$1,258,191	$0.39	$0.24
Large Group	10,995,801	$5,751,837	$2,314,637	$0.52	$0.21
Total	**17,324,161**	**$8,289,917**	**$3,829,510**	**$0.48**	**$0.22**

For each person receiving any form of treatment directly associated with an ASD, the average monthly claim cost during 2013 was $255, ranging from $212 in the individual market to $270 in the large group market. With respect to the population 18 years of age and younger, the average monthly costs of ABA treatments ranged from $126 in the individual market to $169 in the small group market.

It is notable that the average cost of ABA treatment is well below the statutory maximum required coverage, set at an initial rate of $40,000 per year for each covered insured. Average annual ABA treatment costs for those 18 and under equaled $1,704 ($142 * 12), or only 4.3 percent of the cap.

Average Monthly Claim Cost Per Individual Treated for Autism in 2013				
	All Ages		Age 18 and Under	
Market Segment	**All Autism-Related Treatment**	**ABA**	**All Autism-Related Treatment**	**ABA**
Individual	$212	$106	$246	$126
Small Group	$229	$142	$262	$169
Large Group	$270	$109	$307	$133
Total	**$255**	**$118**	**$290**	**$142**

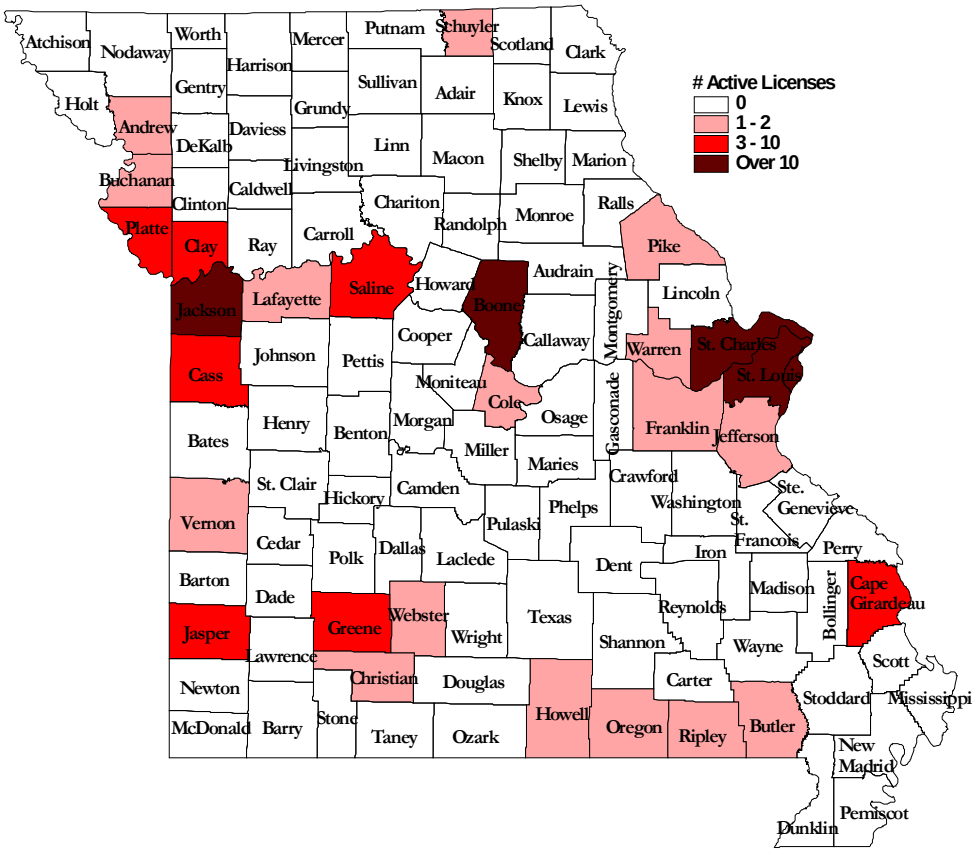
Licensure

House Bill 1311 requires that each behavior analyst and assistant behavior analyst pass an examination and obtain board certification to be eligible for a license to practice in Missouri. The first licenses were issued in December 2010. By mid-January 2014, licenses were issued to 218 behavior analysts, of which 181 were still active at the time of writing. In addition, 41 assistant behavior analysis licenses were issued, of which 23 were still active. Assistants must practice under the supervision of a behavior analyst. Licensed psychologists, not included in the table, may also provide ABA therapy.

Applied Behavior Analyst Licensure in Missouri				
	Behavior Analysts		**Assistant Behavior Analysts**	
Year of License Issued	**Number Issued**	**Cumulative Number Issued**	**Number Issued**	**Cumulative Number Issued**
2010	19	19	0	0
2011	93	112	23	23
2012	49	161	1	24
2013	52	213	14	38
2014 (through 1-21)	5	218	3	41
Total Issued	**218**		**41**	
Number Still Active (as of 1-21)	**181**		**23**	

Most counties, primarily in the rural areas of the state, lack a licensed behavior analyst. Of Missouri's 115 counties, 87 have no resident licensed behavior analyst or assistant behavior analysts.

Number of Active Behavior Analysis Licenses, Including Assistant Behavior Analysts
As of January 21, 2014



Inquiries and Complaints

The DIFP monitors the number of complaints and inquiries received that are related to the autism mandate. Since the mandate was enacted in 2010, DIFP staff responded to 308 contacts by consumers with questions about autism coverage, or who had a complaint against an insurer. Of the 48 complaints, 9 involved licensed insurers over which the DIFP has jurisdiction. Most complaints were related to insurer handling of claims, including claim denials, delays and unsatisfactory settlement amounts. Complaints regarding the autism mandate resulted in over $128,000 in additional payments to consumers.

Consumer Inquiries / Complaints Regarding Autism Mandate 2010 - Present		
Reason	**No. of Complaints / Calls**	**Recoveries**
Complaints		
Premium & Rating	1	
Endorsement/Rider	1	
Willing Provider	1	
Unsatisfactory Settlement on Claim	2	
Denial of Claim	21	$115,974
Usual, Customary, Reasonable – Claim Issue	1	
Claim Delays	3	$12,416
Coverage Question	5	
Abusive Service	1	
Other Issue	12	
Subtotal	**48**	**$128,390**
Other inquiries	212	
Total	**308**	**$128,390**

Future Market Developments

Beginning on January 1, 2014, several reforms to the health insurance market become effective. One reform is the requirement that non-grandfathered individual and small employer group plans (under current Missouri law, groups of 2 to 50), must provide coverage for the Essential Health Benefits (EHBs).

The Secretary of the U.S. Department of Health and Human Services is required to define EHBs to ensure that they are equal in scope to benefits under a typical employer plan. Under current HHS regulations, EHBs are based on the coverage provided under the state's largest small group health plan, by enrollment. This plan is known as the EHB benchmark plan. As outlined by HHS, the EHB benchmark plan must include 10 broad categories of benefits, as well as any state coverage mandates that are applicable to the designated benchmark plan. These identified benefits provide a "floor of coverage" that must be included in all non-grandfathered individual and small group health plans, starting in 2014. Since Missouri's autism coverage mandate applies to the plan currently designated by HHS as the EHB benchmark plan, coverage for ASDs and ABA therapy must be included in non-grandfathered individual and small group health insurance plans beginning in 2014.

Federal law requires that benefits defined as EHBs be offered without annual or lifetime limits on the dollar amount of the coverage, but allows such limits to be converted to another actuarially equivalent limitation. Missouri's autism mandate specifies an inflation-adjusted annual dollar limit on ABA services, but also includes an express prohibition on visit limits. The impact of federal law on the annual limits allowed under Missouri law for ABA therapy after January 1, 2014, is undetermined at the time of this report.

Conclusion

The costs associated with the autism and ABA coverage mandate has to date, been minimal, even as the mandate has led to dramatically expanded coverage and the delivery of medically beneficial services. Applied behavior therapies have been shown to dramatically reduce long-term costs for a significant proportion of individuals diagnosed with an ASD, and to significantly improve their quality of life. The law has achieved its purposes in an unqualified way for every measureable metric.

The DIFP will continue to monitor the marketplace, and provide assistance to consumers with questions or concerns regarding the autism mandate. More information, and resources to assist insurance consumers, can be found on the department's website at http://insurance.mo.gov/consumers/autismFAQ/.

Appendix – Autism Resources

The following links are to resources that may be useful to families, medical providers, or anyone else wishing to learn more about autism.

Autism Speaks works to raise awareness of autism, and their internet page provides a wealth of information about the condition, available services, current research, news, and much more. Their page can be found at http://www.autismspeaks.org/ They maintain a page for Missouri-specific events at http://communities.autismspeaks.org/site/c.ihLPK1PDLoF/b.7512615/k.C037/Missouri_Resources.htm

The **Centers for Disease Control (CDC),** the nation's health protection agency, maintains a page devoted to autism at http://www.cdc.gov/ncbddd/autism/index.html. The CDC also maintains a helpful list of links to other websites to assist families touched by autism at http://www.cdc.gov/ncbddd/autism/links.html.

The **Missouri Autism Coalition** is an alliance of groups and individuals throughout the state that seeks to advance awareness of autism. They can be found at http://www.missouriautismcoalition.com/about_us

Missouri Families for Effective autism Treatment (MO-FEAT) describes its mission as providing "advocacy, education and support for families of the autism community, and to support early diagnosis and effective treatment." It is headquartered in St. Louis, and they maintain a web-page at http://www.mo-feat.org/ MO-FEAT publishes an excellent guide to autism centers and additional medical providers at http://www.mo-feat.org/Files/2012%20Directory.pdf.

Missouri funds four autism centers to promote advancements in research and treatment. The **Thompson Center For Autism & Neurodevelopmental Disorders** is affiliated with the University of Missouri and located in Columbia, http://thompsoncenter.missouri.edu/. The **Knights of Columbus Developmental Center** is hosted by Cardinal Glennon Hospital in St. Louis, http://www.cardinalglennon.com/MedicalSpecialties/Developmental%20Pediatrics/Pages/default.aspx . The **Children's Mercy Hospital & Clinics Developmental & Behavioral Sciences** is located in Kansas City, http://www.childrensmercy.org/Autism/. The fourth center is affiliated with **Southeast Missouri State University** in Cape Girardeau, http://www.semo.edu/autismcenter/

Valuable services are available through the **Missouri Department of Mental Health's** Division of Developmental Disabilities, which serves a diverse population, including those with cerebral palsy, head injuries, certain learning disabilities, as well as autism. To be eligible for services, individuals must be "substantially limited in their ability to function independently." See their page at http://dmh.mo.gov/dd/

The **National Autism Center** describes its mission as "…providing reliable information, promoting best practices, and offering comprehensive resources for families, practitioners, and communities." See http://www.nationalautismcenter.org/about/

Insurance Consumer Hotline

Contact DIFP's Insurance Consumer Hotline
if you have questions about your insurance policy
or to file a complaint against an
insurance company or agent:

difp.mo.gov

800-726-7390

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