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**Autism Insurance Coverage:
Is the Cost of a National Mandate Too Burdensome
in an Uncertain Economy?**

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Autism, or autism spectrum disorder (ASD), is the term used to describe a series of complex neurobiological disorders involving language, social, and sensory processing problems.¹ ASDs include autistic disorder, Asperger syndrome, and pervasive developmental disorder—not otherwise specified (PDD-NOS, including atypical autism); while symptoms may appear the same amongst individual disorders, the symptoms differ in severity, onset of occurrence, and specific nature.² The Centers for Disease Control and Prevention estimates that 1 in 150 eight-year-old children have autism, and advocates claim that autism is the “fastest-growing serious developmental disability in the U.S.”³ Autism affects all racial, ethnic, and socioeconomic groups and is four times more likely to occur in boys than girls.⁴ Disagreement exists within the mental health community as to whether the rise in diagnosis of children with autism is the result of better diagnostic testing, more inclusive classification, or an actual increase in the

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¹ Trudy Steuernagel, *Increases in Identified Cases of Autism Spectrum Disorders*, 16 J. OF DISABILITY POL'Y STUD., 138, 138 (2005); AUTISM SPEAKS, ARGUMENTS IN SUPPORT OF PRIVATE INSURANCE COVERAGE OF AUTISM-RELATED SERVICES 4 (Oct. 24, 2007), http://www.autismvotes.org/atf/cf/%7B2A179B73-96E2-44C3-8816-1B1C0BE5334B%7D/arguments_for_private_insurance_coverage.pdf.

² CTRS. FOR DISEASE CONTROL & PREVENTION, AUTISM INFORMATION CENTER: AUTISM SPECTRUM DISORDERS OVERVIEW (Feb. 9, 2007), <http://www.cdc.gov/ncbddd/autism/overview.htm> [hereinafter CDC].

³ CDC, *supra* note 2; AUTISM SPEAKS, *supra* note 1, at 4.

⁴ CDC, *supra* note 2.

prevalence of the disorder.⁵ Research has shown that autism can be detected as early as eighteen months and early intervention will significantly improve a child's development.⁶

Until recently, the high cost of diagnosing and providing subsequent therapies was not covered by insurance, and many families needed to make significant financial sacrifices so that they could afford treatment.⁷ According to the Autism Society of America, a family could spend as much as \$5 million caring for a child with autism during the child's lifetime.⁸ The Harvard School of Public Health tallies the lifetime cost of autism treatment at about \$3.2 million per person, totaling \$35 billion per year to care for all persons with autism.⁹ Autism Speaks, a national advocacy group and proponent of state mandated insurance coverage, remarks that the financial burden may require these families to take out second mortgages, live with other family members, and possibly file for bankruptcy in order to pay for treatment and therapy.¹⁰

Members of Autism Speaks, who are integral players in the push for autism insurance coverage mandates, have personal connections to the disorder and experience the frustrations associated with the high cost of treatment, which families sometimes simply cannot afford.¹¹ For instance, Autism Speaks Illinois

⁵ Steuernagel, *supra* note 1, at 138.

⁶ CDC, *supra* note 2; *see also* Autism Society of America, Characteristics of Autism, http://www.autism-society.org/site/PageServer?pagename=about_what_is_char (last visited Mar. 29, 2009) (“[C]hildren with autism can learn and function normally and show improvement with appropriate treatment and education.”).

⁷ *See* Val Willingham, *Parents Press for Autism Insurance Coverage*, CNN, <http://www.cnn.com/2008/HEALTH/conditions/10/17/autism.insurance/index.html> (last visited Mar. 29, 2009).

⁸ *Id.*

⁹ Barbara Kantrowitz & Julie Scelfo, *Growing Up with Autism; Teenagers and Young Adults are the Emerging Face of Autism as the Disorder Continues to Challenge Science and Unite Determined Families*, NEWSWEEK, Nov. 27, 2006, available at http://autism.pbisillinois.org/IATTAP_newsweek_growing_up_with_autism27NOV06.pdf; Press Release, Harvard School of Public Health, Autism Has High Costs to U.S. Society (Apr. 25, 2006) (on file with Harvard School of Public Health), available at <http://www.hsph.harvard.edu/news/press-releases/2006-releases/press04252006.html>.

¹⁰ Willingham, *supra* note 7; *see* AUTISM SPEAKS, *supra* note 1.

¹¹ Telephone Interview with Lee Jorwic, Illinois Chapter Advocacy Chair for Autism Speaks, in Chicago, Ill. (Feb. 12, 2009). Lee Jorwic is the current Advocacy Chair for Autism Speaks and was formerly President of the Chicago Chapter of Autism Speaks and President of Cure Autism

Chapter Advocacy Chair Lee Jorwic and his wife Teri have spent approximately \$25,000 to \$30,000 per year on treatment for their son Christopher, who was diagnosed with autism in 1993.¹² Christopher's treatment encompassed over four and a half years of private therapy, including more than forty hours per week of personal Applied Behavioral Analysis (ABA) therapy.¹³ ABA, a particular method of one-on-one therapy, is costly and controversial, yet most promising for those children who are diagnosed at an early age.¹⁴ ABA is highly repetitive and intensive, (requiring up to eight hours a day, forty hours a week), and estimates of costs vary greatly.¹⁵ Parents lobbying for coverage of this therapy argue that autistic children who receive ABA will be able to care for themselves, even if only the basic activities of daily living.¹⁶ As a result, these children may be less dependent on public aid such as Medicaid as they grow older.¹⁷

Only a handful of states require private insurance companies to provide coverage for behavioral treatment services for autism, such as ABA therapy.¹⁸ Amongst those states that have mandates in place, the coverage limits and maximum ages of eligibility for benefits vary.¹⁹ Due to this partial or complete lack of coverage, Autism Speaks launched a grass-roots campaign in several states.²⁰ Its latest success occurred on December 12, 2008, when Illinois passed Public Act 95-1005 (215 ILCS 356z. 14) requiring all group and individual health insurance policies and HMO contracts to provide "coverage for the diagnosis and

Now. He has been working on the grass-roots campaign in Illinois for insurance coverage for the past six years. Mr. Jorwic's reason for becoming such a prominent advocate for autism and insurance coverage is simple, clear, and humbling: "Teri and I have met people [who] over the years just get devastated by [the high cost of ABA therapy] . . . I wanted to do something for other people, because so many people are devastated...." *Id.*

¹² *Id.*

¹³ *Id.*

¹⁴ John Donovan, *Insurance vs. Autism: For Parents, Insurance is a Personal Fight*, ABC NEWS, Mar. 24, 2008, <http://abcnews.go.com/Health/story?id=4515825>; Willingham, *supra* note 7.

¹⁵ Donovan, *supra* note 14; Willingham, *supra* note 7.

¹⁶ Donovan, *supra* note 14.

¹⁷ Donovan, *supra* note 14; *See also* Kantrowitz & Scelfo, *supra* note 9.

¹⁸ HOLLY BORTFELD, TALK ABOUT CURING AUTISM, INSURANCE COVERAGE FOR BIOMEDICAL & TRADITIONAL AUTISM TREATMENTS 25 (Oct. 2008), <http://www.tacanow.org/resources/autism-insurance/insurance-coverage-for-autism.pdf>.

¹⁹ *Id.*

²⁰ Telephone Interview with Lee Jorwic, *supra* note 11.

treatment of autism spectrum disorders for children under 21, establishing an annual benefit of \$36,000 for services....”²¹ According to Jorwic, Autism Speaks focused on Illinois as a pivotal state because of the prevalence of major insurance companies based in the state.²² Autism Speaks hopes that passing the law in Illinois will be the tipping point, and the arguments and information which persuaded Illinois legislators will be nationally disseminated and serve as a catalyst for the enactment of similar laws in other states.²³

Nevertheless, the main opponent of autism advocate groups will continue to be the insurance industry, according to Jorwic.²⁴ Specifically, the Council for Affordable Health Insurance argues that passage of such mandates will inevitably lead to increased cost of insurance premiums and therefore put the cost of coverage out of the reach of many already struggling Americans.²⁵ The Joint Legislative Audit and Review Commission (JLARC) of Virginia reported that insurance premiums would increase by \$4.88 per month if the state were to pass its version of the autism insurance mandate.²⁶ Critics argue the increase, which may not appear significant in theory, will overburden small-business owners in reality since they already are finding it difficult to provide quality health insurance for their employees.²⁷

Autism advocates argue that coverage will impact insurance premiums minimally at best—for instance, Indiana premiums only increased between .5% and 1% after the passage of the state legislation.²⁸ Additionally, such advocates

²¹ ILL. DEP’T. OF FIN. & PROF’L REG., ILLINOIS INSURANCE FACTS; INSURANCE COVERAGE FOR AUTISM (Dec. 2008), <http://www.idfpr.com/DOI/pressRelease/pr08/AutismFactSheet.pdf>.

²² Telephone Interview with Lee Jorwic, *supra* note 11.

²³ *Id.*

²⁴ *Id.*

²⁵ Carla K. Johnson, *Parents Press States for Autism Insurance Laws*, ABC NEWS, Oct. 20, 2008, available at <http://abcnews.go.com/Health/wireStory?id=6068425>.

²⁶ JOINT LEGISLATIVE AUDIT & REVIEW COMMISS’N, EVALUATION OF HOUSE BILL 83: MANDATED COVERAGE OF AUTISM SPECTRUM DISORDERS 8 (Sept. 29, 2008), <http://jlarc.state.va.us/Meetings/Other/Autism.pdf>.

²⁷ Keith D. Cheatham, *Time for Autism Insurance? – No*, RICHMOND TIMES-DISPATCH, Jan. 4, 2009, available at http://www.timesdispatch.com/rtd/news/opinion/columnists/article/CHEATHAM105_20090102-204431/167616/.

²⁸ Telephone Interview with Lee Jorwic, *supra* note 11.

argue that states with the highest maximum yearly benefits only will see a modest increase in the cost of annual premiums, approximately \$50 per policy holder.²⁹

According to a study conducted by the American Association on Mental Retardation, children with autism were more likely to encounter problems accessing specialty care from a medical doctor than children with mental retardation.³⁰ Over a quarter of the children with autism reportedly had health plan-based and provider-based access problems, including the inability to find “skilled and experienced specialty doctors.”³¹ Further, under the current system, even when a person with autism lives in a state that has implemented a mandate, coverage is not necessarily guaranteed.³² A federal mandate providing one comprehensive, cohesive plan throughout the country, such as then Senator Obama’s draft bill entitled the Autism Treatment Acceleration Act of 2008, would minimize the complexities and ease the confusion associated with interpreting varying state mandates for employers, plan providers, doctors, other medical providers, and parents so that autistic children could be treated adequately.³³

A federal mandate does not constitute socialized medicine nor an attempt to further burden American workers or small business owners with exorbitant insurance premiums. Rather, a community of healthcare advocates, parents, and concerned citizens views a national law as a vehicle to provide the best available treatment for special needs children.³⁴ Children who never are given the opportunity to learn necessary life skills will become adults who are not self-sufficient and likely will rely upon public aid to meet their needs.³⁵ Despite fears that private citizens cannot withstand increased insurance expenses in a

²⁹ AUTISM SPEAKS, *supra* note 1, at 15.

³⁰ Marty Wyngaarden Kraus et al., *Access to Specialty Medical Care for Children with Mental Retardation, Autism, and Other Special Health Care Needs*, 41 MENTAL RETARDATION 329, 333 (2003).

³¹ *Id.* at 334.

³² BORTFELD, *supra* note 18, at 25 (clarifying that it is the state in which the policy is written and funded whose laws govern the insurance).

³³ See generally Autism Treatment Acceleration Act of 2008, 110th Cong. (2d Sess. 2008), available at <http://www.autismvotes.org/atf/cf/%7B2A179B73-96E2-44C3-8816-1B1C0BE5334B%7D/Obama%20federal%20autism%20reform.pdf>.

³⁴ See Telephone Interview with Lee Jorwic, *supra* note 11.

³⁵ *Id.*

challenging economy, spending additional money today makes more sense than further stressing an already strained public aid system in the future. Ultimately, a federal mandate likely would reduce the monetary burden on the public aid system if these children learn to function independently at a young age without the need for lifelong support.