

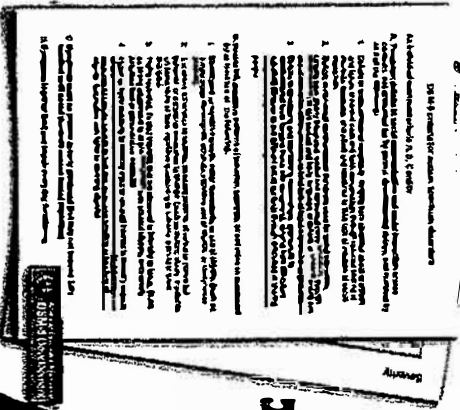
Autism Insurance and HB 2744

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 Associate Director of State Government Affairs
 Autism Speaks
 Senate Financial Institutions and Insurance Committee
 March 21, 2014



Diagnosing Autism

- The American Academy of Pediatrics recommends **screening** every child for autism at their 18, 24 and 30 or 36 month checkups.
- Autism is **diagnosed** by a medical doctor; usually by a developmental pediatrician, psychologist, pediatric neurologist or team of developmental specialists.

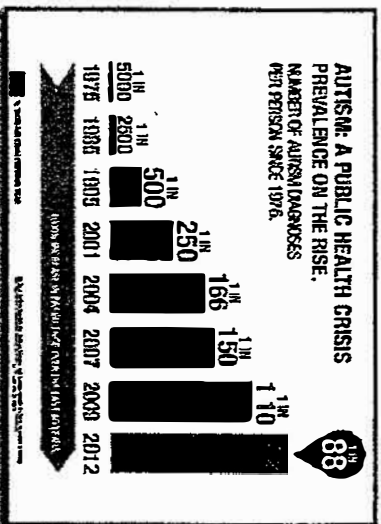


What is Autism?

- Autism is a medical condition, brought on through no fault of the family.
- Autism affects a person's communication abilities and social skills, and often causes **repetitive patterns of behavior** and a narrow range of interests.
- Its symptoms range from mild to severe.



Prevalence of Autism



Autism is an epidemic and a public health crisis

Autism is Treatable

- Although there is no known cure for autism, it can be treated so that the symptoms are not disabling
 - A non-verbal child can gain the ability to communicate
 - A non-social child can gain interaction skills.
 - Maladaptive behaviors can be eliminated
- Early intervention is critical



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Applied Behavior Analysis

- Behavior Analysis is the science that identifies principles of behavior
- Applied Behavior Analysis (ABA) applies the science of behavior analysis to a clinical setting
- Different techniques of ABA (e.g. discrete trial, verbal behavior, pivotal response, natural language paradigm)
- Common features
 - structured
 - collect data for target skills or behaviors
 - provide positive strategies for changing responses or behaviors



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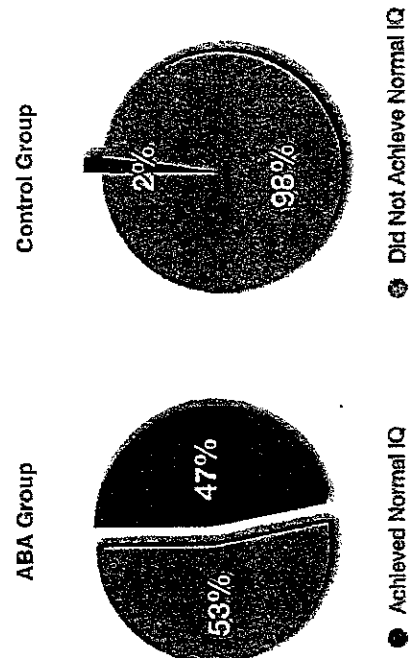
Treatment

- Early diagnosis and treatment are critical to a positive outcome for individuals with an autism spectrum disorder (ASD)
- Treatment is prescribed by a licensed physician or licensed psychologist:
 - Behavioral Health Treatment, e.g. Applied Behavior Analysis (ABA) Therapy
 - Speech, Occupational and Physical Therapy
 - Psychological, Psychiatric, and Pharmaceutical Care



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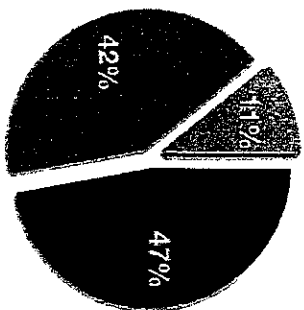
Efficacy of ABA Therapy



Levin, O.L. (2007). Behavioral treatment and normal subjective and intellectual functioning in young autism children. *Journal of Clinical Child Psychology*, 35

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Educational Placement for Group that Received ABA



- Maintained with No Support
- Low-Intensity Special Education Placement (for autism or intellectual disability)
- High-Intensity Special Education Placement (for autism or intellectual disability)

Figure 3.1.1.19.8. Some additional information extracted and re-arranged from a young white paper
Journal of Consulting and Clinical Psychology, 55



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ABA Endorsements

UNITED STATES SURGEON GENERAL
(1999)
"Thirty years of research demonstrated the efficacy of applied behavioral methods in reducing inappropriate behavior and in increasing communication, learning, and appropriate social behaviors."

CENTERS FOR DISEASE CONTROL AND PREVENTION (2012)
"A notable treatment approach for people with an ASD is called applied behavior analysis (ABA). ABA has become widely accepted among health care professionals..."

CENTERS FOR MEDICARE AND MEDICAID
(2011)
"... controlled trials have shown both the efficacy of programs based in the principles of ABA and that certain individual characteristics (age, IQ, and functional impairment) are associated with positive outcomes."

NATIONAL INSTITUTE OF MENTAL HEALTH (2011)
"One form of a widely accepted treatment is applied behavior analysis (ABA). The goals of ABA are to shape all children's new behaviors, start as learning to speak and play, and reduce undesirable ones."

AMERICAN PSYCHOLOGICAL ASSOCIATION PRACTICE ORGANIZATION
(2012)
"The use of applied behavior analysis has grown substantially in the last decade, leading to a 70% increase in the number of behavior analysts in the field. This increase is due to the number of children diagnosed with an autism spectrum disorder and to the recognition of the effectiveness of behavior analytic services."

NATIONAL INSTITUTE OF NEUROLOGICAL DISORDERS AND STROKE (2012)
"Therapies and behavioral observations and designed to remedy specific symptoms and ease living about intellectual impairment... Therapies use highly structured and intensive skills training sessions to help children develop social and language skills, such as Applied Behavioral Analysis"

AMERICAN ACADEMY OF PEDIATRICS
(2012)
"An example of a demonstrated, effective treatment for ASD is Applied Behavior Analysis, or ABA. ABA uses behavioral health principles to increase and maintain positive adaptive behavior and reduce negative behaviors or narrow the conditions under which they occur."



Applied Behavior Analysis

- ABA is the most commonly prescribed evidence-based treatment for ASD
- Decades of research demonstrate the effectiveness of ABA therapy for autism
- Endorsed by leading national health agencies; pediatric, neurologic and psychological organizations

Many insurers still deny coverage for ABA based on the assertion that ABA therapy is "experimental." *This assertion is simply not supported by science*



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Federal ABA Endorsements

THE U.S. OFFICE OF PERSONNEL MANAGEMENT (2012)

"The OPM Benefit Review Panel recently evaluated the status of Applied Behavior Analysis (ABA) for children with autism. Previously, ABA was considered to be an educational intervention and not covered under the FEHB Program. The Panel concluded that there is now sufficient evidence to categorize ABA as medical therapy. Accordingly, plans may propose benefit packages which include ABA."

TRICARE

Military insurance (Tricare) covers autism and specifically includes a benefit for Applied Behavior Analysis therapy.



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When Coverage is Denied

- Because ABA therapy must be administered intensively (sometimes 40 hours per week) it is quite expensive.
- Parents are forced to pay out-of-pocket to provide their children comprehensive ABA therapy, which typically lasts 3-4 years.
- Often financially devastating to families - most affected children go without or receive only a fraction of prescribed treatment
- These children end up in costly special education programs, and dependent on state funded adult disability services.



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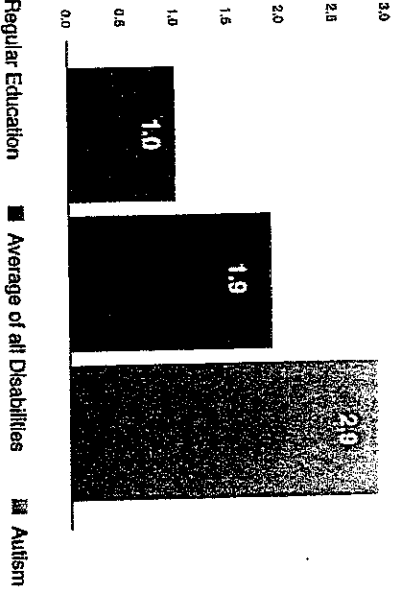
Autism Insurance Reform Saves the State Money

- Without appropriate treatment, the lifetime cost to the state has been estimated to be \$3.2 million per child with ASD (Ganz, 2007)
- The cost of autism insurance reform could be recovered through reductions in special education and medical expenditures alone. (Oliver Wyman)
- The high cost option is to oppose autism insurance reform.



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Annual Per Pupil Spending Ratio (disability versus average regular education student)

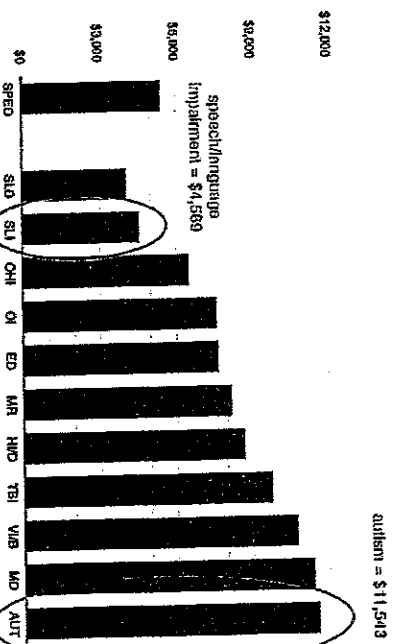


Charters, J. (2011). *Real Expenditures for Students with Disabilities, 1997-2007*. Report for the U.S. Department of Education, Office of Special Education Programs. Retrieved from www.doe.gov



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Students with autism (AUT) have the highest annual per pupil expenditures for special services



SPED = average special education student; SLD = specific learning disability; SLI = speech/language impairment; OH = other health impairment; OI = orthopedic impairment; ED = emotional disturbance; MIR = mental retardation; HDC = hearing impairment/deafness; TBI = traumatic brain injury; VIB = visual impairment/blindness; MD = multiple disabilities; AUT = autism

Charters, J. (2011). *Real Expenditures for Students with Disabilities, 1997-2007*. Report for the U.S. Department of Education, Office of Special Education Programs. Retrieved from www.doe.gov



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Special Education Cost Savings as a Result of Providing Comprehensive ABA for Autism

Children with autism who receive comprehensive ABA

Educational placement upon starting first grade	Number of children	Annual SPED cost	Total Annual SPED cost
mainstream with no support	47	\$0	\$0
low Intensity Special Education Placement	42	\$4,589	\$191,898
high Intensity Special Education Placement	11	\$11,943	\$128,973
Total			\$318,873

WITH ABA

Children with autism who do not receive comprehensive ABA

Educational placement upon starting first grade	Number of children	Annual SPED cost	Total Annual SPED cost
mainstream with no support	2	\$0	\$0
low Intensity Special Education Placement	0	\$4,589	\$0
high Intensity Special Education Placement	98	\$11,943	\$1,181,214
Total			\$1,181,214

WITHOUT ABA

For every 100 children with autism who receive comprehensive ABA, the State will save \$812,343 per year in special education services alone.

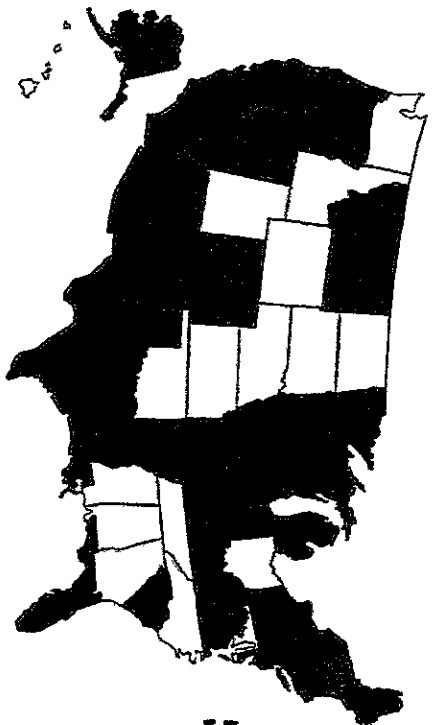
Source: D. L. Berry, M.D., et al. (2007). *Special Education Services for Children with Autism: A Review of the Literature*. Washington, DC: U.S. Department of Education, Office of Special Education.

The Cost of Autism Insurance Reform

State	Number of covered lives	Total Claims Paid	PM/PM cost
South Carolina	397,767	\$2,042,394	\$0.43
Illinois	170,790	\$197,290	\$0.10
Louisiana	149,477	\$722,828	\$0.40
Florida	386,203	\$1,748,849	\$0.38
Arizona	130,000	\$388,662	\$0.26
Missouri	1,429,153	\$6,555,602	\$0.38
Kansas	99,465	\$309,216	\$0.26
Average Cost			\$0.31

References: Data collected by Autism Speaks from state sponsors responsible for administering the Endicott Leahy Benefits Program (2013); Missouri Department of Insurance, Financial Institutions and Professional Regulation (2012); and the Kansas Department of Health and Environment (2012)

State Response



33 other states require coverage for ABA for autism

Effect on Premiums

Annual Report to the Missouri Legislature
Insurance Coverage for Autism Treatment & Applied Behavior Analysis
Submitted October 1, 2012

- Claims incurred for treatment of ASD represent < 0.2% of total claims
- "Given that treatment for autism represent less than 0.2% of overall claims costs, it is very unlikely that such costs will have an appreciable impact on insurance premiums."

- Missouri DIRP

Cost of Coverage

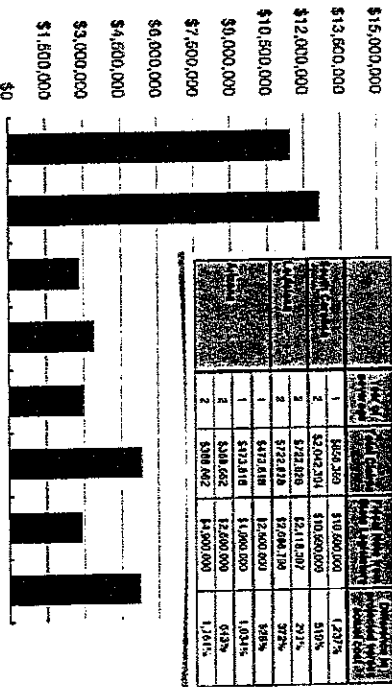
If the out of pocket cost of treatment can be as high as \$50,000 per child per year, how can the reported claims data be so low, i.e. 31 cents PMPM?

- Autism is a spectrum and treatment is individualized based on the severity and individual needs of the affected individual.
- Utilization of benefits is not 100%

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Projected vs Actual Costs

■ Actual Cost ■ Fiscal Note from State Legislature



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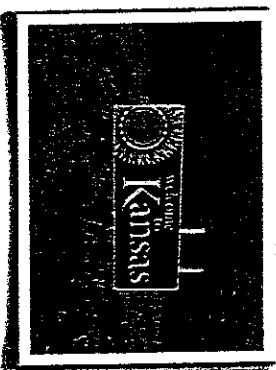
Utilization

- Of the estimated number of affected individuals, how many access treatment?
- Disease Prevalence ≠ Treated Prevalence
- Based on claims data collected by Autism Speaks, estimated benefit utilization is 30-50%. (Minnesota providers report 20%.)
- Contributing factors?
 - undiagnosed individuals
 - parent choice
 - higher functioning
 - socioeconomic status

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Autism in Kansas

- The CDC reports that the national prevalence of autism is 1:88
- 8,413 Kansas children less than age 19 are estimated to have autism.



www.kshhshealthfacts.org (2010 population data)

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KS Autism Insurance Pilot Project

- KSA 75-6524 enacted April 2010
- Passed overwhelmingly
 - Senate: 40 - 0
 - House: 88 - 31 - 6
- Covers diagnosis and treatment of autism, including behavioral health treatments such as ABA
 - \$36,000/yr age 0-7
 - \$27,000/yr age 7-19
- Kansas legislature acknowledged
 - importance of early diagnosis and intervention for autism
 - the efficacy and medical necessity of evidenced based treatments such as ABA



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Purpose of the Pilot Project

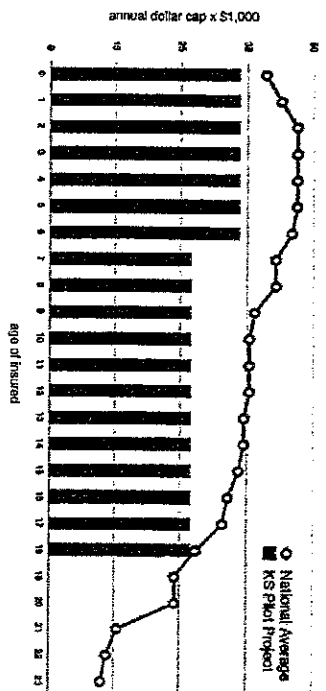
- Before extending coverage to all state regulated health plans, the legislature wanted to determine the cost to the State of Kansas.
- The cost to the State of Kansas is the cost of providing coverage to state employees.



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Autism Insurance Laws

Annual Dollar Caps per Age of Insured



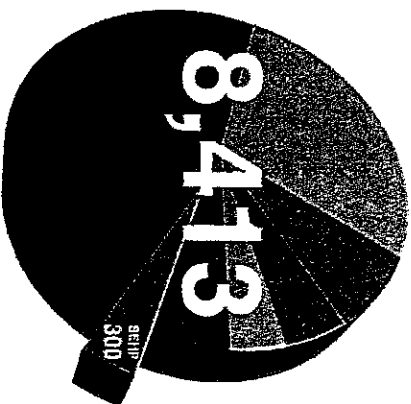
Annual dollar caps for the Kansas pilot project are below the national average (32 states) at every age group 0-23.



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KS Autism Insurance Pilot Project

- Provided coverage for members of the State Employees Health Plan (SEHP)
- Only 4% (about 300) of children with autism in Kansas are covered by the SEHP



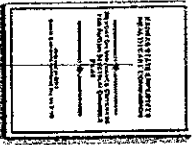
Kansas Children with ASD (age 0-19)

- Self-Funded
- Other Public (e.g. TRICARE)
- Medicaid
- Uninsured
- Individual
- Fully Insured Large Group
- Fully Insured Small Group
- SEHP

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Cost of the Kansas Autism Pilot Project

	2011	2012	2013
Total Claims Paid	\$169,430	\$309,216	\$326,907
Total Covered Lives	99,396	99,465	99,465
Unique Claimants	126	126	129
PNPM	\$0.14	\$0.26	\$0.27



data obtained from Kansas Department of Health and Environment

- SEHIC has voted annually to continue coverage
- The SEHIC autism benefit was made permanent in 2013

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Delayed Implementation

- Why do children covered by a small group or individual plan have to wait an additional year to access the benefit?

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Summary of HB 2744

- large group market- Jan 1, 2015
- grandfathered small group and individual markets - Jan 1, 2016
- covers ABA up to 25 hours/week for 4 years from time of diagnosis (0-5); then 10 hours/week until age 12
- no caps on other treatments
- licensure proposal

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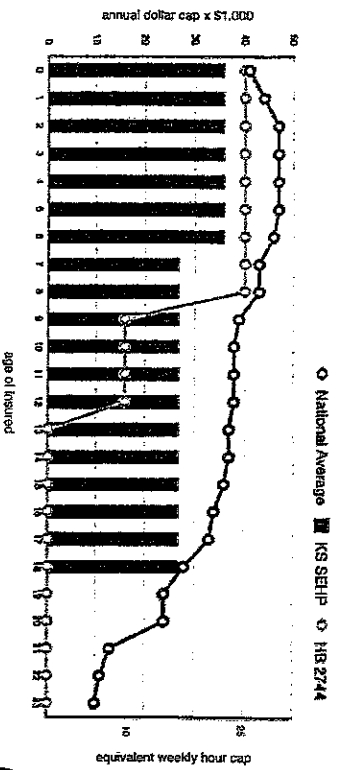
Hour cap on ABA

- Standard of care dictates that the prescription for ABA therapy is individualized and based upon severity (range = 25-40 hours/week)
- While more intense "comprehensive" ABA therapy to address multiple treatment goals is most commonly prescribed at a younger age, "focused" ABA therapy to address isolated maladaptive behaviors may be required at times throughout the lifespan.

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Autism Insurance Laws

Annual Dollar Caps per Age of Insured



Annual dollar caps for the Kansas pilot project and HB 2744 are below the national average (32 states) at every age group 0-23.

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Diagnostic Criteria

- HB 2744 defines “autism spectrum disorder” using diagnostic criteria from the DSM 4
- **These criteria are outdated and defunct** since publication of the most recent version of the DSM (i.e., DSM 5) in May of 2013.
- Dr. Kathy Ellerbeck

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Existing SEHP Coverage

- Existing SEHP-approved ABA provider rates
 - consultant level ABA provider = \$70/hour
 - line therapist (or IIS level provider) = \$25/hour
- the standard of care is that for every 10 hours of direct treatment (i.e., from a line therapist) that there be 1-2 hours of consultant level supervision.
 - 1.5 hours x consultant reimbursement rate (\$70/hour) = \$105
 - 10 hours x line therapist reimbursement rate (\$25/hour) = \$250
- Blended reimbursement rate = $\$355 \div 11.5 \text{ hours} = \$30.87/\text{hour}$
- $\$36,000/\text{year} \div \$30.87/\text{hour} = 1,166 \text{ hrs}/\text{year} = 22.4 \text{ hrs}/\text{week}$

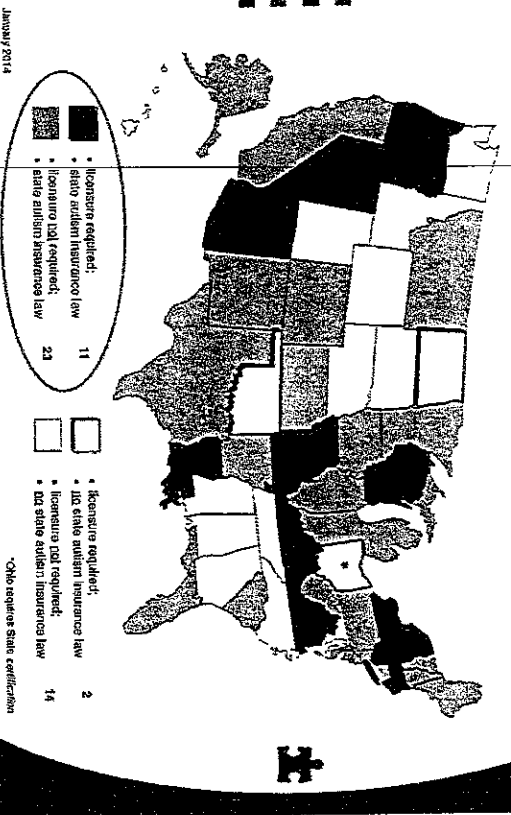
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Licensure

- As evidenced by 23 states, including the Kansas State Employee Health Plan, licensure of ABA providers is not required for reimbursement of ABA therapy
- The licensure proposal in HB 2744 has not been adequately vetted by the provider community;
- Problematic issues with the proposal may adversely impact access to ABA in Kansas
- Dr. Linda Heitzman-Powell

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Licensure of Behavior Analysts is Required in 13 States



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Recommendations

- Implementation date of Jan 1, 2015 for all markets
- Define "autism spectrum disorder" based on current criteria (Dr. Ellerbeck)
- Consider delaying and/or improving the licensure proposal based on BACB model legislation (Dr. Heitzman-Powell)
- Consider providing coverage for ABA through age 18, consistent with SEHP

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Contact Information

Autism Speaks State Government Affairs

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About Autism Speaks

Autism Speaks is the world's leading autism science and advocacy organization, dedicated to funding research into the causes, prevention, treatments and a cure for autism. Increasing awareness of autism spectrum disorders, and advocating for the needs of individuals with autism and their families.

Autism Votes is an Autism Speaks initiative; a comprehensive grassroots advocacy program, coordinating activist efforts in support of federal and state legislative initiatives.

For more information, please visit www.autismvotes.org and www.autismspeaks.org

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