Legislation of Interest to the Autism Community in Kansas

Beyond the Diagnosis: Autism Across the Lifespan
October 7 & 8, 2011

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Update

- Status of Kansas Autism Insurance Reform
- Impact of Federal Health Care Reform
- Kansas Autism Waiver
- Kansas Developmental Disability Waiver
- Combatting Autism Reauthorization Act
Kansas Autism Task Force formed (2007)

Kate born (1999)
Kate diagnosed (2001)

Autism Prevalence On The Rise*
There has been a 600% increase in prevalence over the last two decades.

www.AutismSpeaks.org

*Recent research has indicated that changes in diagnostic practices may account for at least 25% of the increase in prevalence over time, however much of the increase is still unaccounted for and may be influenced by environmental factors.
Autism Facts

- Early diagnosis and treatment are critical to a positive outcome for individuals with an autism spectrum disorder (ASD)

- **With appropriate treatment**
  - 47% will mainstream in regular education without an aid (vs 2% without appropriate treatment)
  - 42% will require low level intensity SPED
  - 11% will require high intensity SPED
Kansas Autism Task Force
Findings

• inequities in health insurance coverage create one of the most significant barriers to appropriate early intervention for children with autism spectrum disorders in Kansas.

• No private health insurance carrier in Kansas consistently covers the diagnosis and medically necessary treatments for ASD.
What happens when insurance companies deny coverage for the treatment of autism?
Financial Ruin

• The out of pocket cost of treatment often exceed $50,000 per year

• Financially devastating to families - most go without or receive a fraction of prescribed treatment

• **Without appropriate treatment**, the lifetime cost to the state has been estimated to be **$3.2 million** per child with ASD
KS Task Force Recommendation

- introduce legislation (SB 12 & HB 2367)
- financial cap of $75,000 only on ABA
- unlimited coverage for other medically necessary autism treatments (e.g. ST, OT)
- through age 21
- exempt from the “pilot project” statute
The “Pilot Project” Statute

- **KSA 40-2249a**
- to assess cost and utilization of proposed coverage
Actual Claims Data
BCBS of Minnesota (2007)

• In effect since 2001

• Terms
  • No dollar cap
  • No age cap

• Premium impact per member per month
  • $0.83 commercial market
  • $0.79 public programs

• Average annual cost for behavioral health treatment = $30,000
Actual Claims Data
South Carolina SEHP

- Implemented Jan 2009
- Terms
  - $50,000 cap on ABA
  - To age 16

- Premium impact per SEHP member per month
  - 2009: 20 cents
  - 2010: 44 cents
"LA LA LA LA LA...NOT LISTENING!"
KS House Bill (HB) 2160

• KSA 75-6524 effective Jan 1, 2011
• Only applies to State Employees as per the pilot project
• Very low financial caps on services

Governor Mark Parkinson
April 19, 2010
# KS HB 2160 vs MO HB 1311

<table>
<thead>
<tr>
<th></th>
<th>Kansas</th>
<th>Missouri</th>
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<tbody>
<tr>
<td><strong>Bill Number</strong></td>
<td>HB2160</td>
<td>HB1311</td>
</tr>
<tr>
<td><strong>Date Passed</strong></td>
<td>Apr 19, 2010</td>
<td>Jun 10, 2010</td>
</tr>
<tr>
<td><strong>Date Effective</strong></td>
<td>Jan 1, 2011</td>
<td>Jan 1, 2011</td>
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<tr>
<td><strong>Scope of Coverage</strong></td>
<td></td>
<td>Fully funded insurance plans and State employees; must be offered to individual plans but does not apply automatically</td>
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<tr>
<td><strong>Limitations on Coverage</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Age Limits</strong></td>
<td>Under 19</td>
<td>ABA is limited to age 18 Other treatments are <strong>not</strong> limited by age</td>
</tr>
</tbody>
</table>
| **Annual Dollar Limit** | - age 0 to 6: $36,000 per year - age 7 to 18: $27,000 per year | **ABA is limited to $40,000 per year**

*Limits are cumulative (i.e. all services count towards the dollar cap)*

*maximum benefit limit may be exceeded, upon prior approval by the health benefit plan, if the provision of applied behavior analysis services beyond the maximum limit is medically necessary for such individual*
Scope of Coverage: KS vs MO

Kansans with ASD (age 0-19) = 6,935
- NOT eligible for coverage under HB 2160 (98%)
- Eligible for coverage under HB 2160 (2%)

Missourians with ASD (age 0-18) = 15,391
- NOT eligible for coverage under HB 1311 (65%)
- Eligible for coverage under HB 1311 (35%)
Limitations on Coverage

KS out of pocket expense = $28,000

MO out of pocket expense = $5,000

$36,000 cumulative cap

$40,000 cap applies only to ABA.

There is no financial cap on other autism-related services.
What would **YOU** do?
After the pilot project?

March 1, 2012

legislature will receive 2011 claims data from SEHP for review.

Will provisions of HB 2160 continue for SEHP and extend to fully funded insurance policies?

- YES
  beginning July 1, 2013

- NO

Need more information?

40-2249a. Same; state employee group pilot project for new mandated health benefits. (a) After July 1, 1999, in addition to the requirements of K.S.A. 40-2248 and 40-2249, and amendments thereto, any new mandated health insurance coverage for specific health services, specific diseases or for certain providers of health care services approved by the legislature shall apply only to the state health care benefits program, K.S.A. 75-6501, et seq., and amendments thereto, for a period of at least one year beginning with the first anniversary date of the state health care benefits program subsequent to approval of the mandate by the legislature. On or before March 1, after the one year period for which the mandate has been applied, the Kansas state employees health care commission shall submit to the president of the senate and to the speaker of the house of representatives, a report indicating the impact such mandated coverage has had on the state health care benefits program, including data on the utilization and costs of such mandated coverage. Such report shall also include a recommendation whether such mandated coverage should continue for the state health care benefits program or whether additional utilization and cost data is required.

(b) The legislature shall periodically review all health insurance coverages mandated by state law.
What is 2 years for a child with autism?

- A chance for mainstream regular education versus special education
- A chance to be a productive tax-paying Kansan versus being dependent upon a lifetime of adult disability services
November 2003
Age: 4 years 3 months

Diagnosed with Autism
Jul 10, 2001

Home Based Intensive Behavioral Therapy (ABA, Speech Therapy, Occupational Therapy)
Nov 1, 2001 – Jan 1, 2005

Preschool
Aug 15, 2002 – May 28, 2004

Two years of ABA
Nov 24, 2003

“seeking interaction”
“great eye contact”
“stayed on topic”
Update on Pilot Project

- 93 children served
- Coverage for SEHP members has been guaranteed through December 2012
- Six month claims data from KDHE:

<table>
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<tr>
<th>Description</th>
<th>Value</th>
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<tr>
<td>Total number of SEHP members</td>
<td>100,000 +</td>
</tr>
<tr>
<td>Cost of HB 2160 to date (6 months)</td>
<td>$51,487.71</td>
</tr>
<tr>
<td>Cost of HB 2160 per month</td>
<td>$8581.29</td>
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<tr>
<td>Cost of HB 2160 per SEHP member per month</td>
<td>&lt; 9 cents</td>
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Arguments in favor of Higher Financial Caps

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<thead>
<tr>
<th></th>
<th>Minnesota</th>
<th>South Carolina</th>
<th>Missouri</th>
<th>Kansas</th>
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<tbody>
<tr>
<td><strong>Annual Cap</strong></td>
<td>none</td>
<td>$50,000 (for ABA therapy)</td>
<td>$40,000 (for ABA therapy)</td>
<td>$30,000 (cumulative services)</td>
</tr>
<tr>
<td><strong>Age Limit</strong></td>
<td>no age limit</td>
<td>16</td>
<td>18</td>
<td>19</td>
</tr>
<tr>
<td><strong>Treatment Covered</strong></td>
<td>includes ST, OT and ABA</td>
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</tr>
<tr>
<td><strong>existing data on impact on premium</strong></td>
<td><strong>83 cents</strong> per member per month</td>
<td><strong>44 cents</strong> per member per month</td>
<td>NA</td>
<td>&lt; 9 cents* per member per month</td>
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<tr>
<td><strong>data source</strong></td>
<td>2007 Blue Cross Blue Shield (BCBS) Minnesota Actuarial reports</td>
<td>APS Healthcare</td>
<td>NA</td>
<td>Kansas Department of Health and Environment (KDHE)</td>
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*ST = speech therapy; OT = occupational therapy; ABA = Applied Behavior Analysis therapy

* first 6 months
Summary

• The disparity between Kansas and Missouri autism insurance legislation is deleterious to the Kansas autism community and the Kansas economy

• If any financial cap is imposed on covered treatments, it must not be cumulative

• Continuation of the “pilot project” is not necessary for this issue and delays provision of appropriate treatment to thousands of Kansas children with autism for at least 2 years

• Enacting a bill comparable to Missouri is not cost prohibitive
It is imperative that the 2012 Kansas Legislature enact a bill that is comparable to Missouri HB 1311 and takes effect July 2012 or sooner.
Federal Health Care Reform

- Prevents exclusion of pre-existing conditions
- Limits insurers’ ability to set annual and lifetime dollar caps on coverage (may affect state mandate limits)
- “behavioral health treatments” must be included in the essential benefits package as of 2014
  - plans offered by state-based exchanges
  - individual and small group plans outside the exchange
  - does NOT include self-funded plans

autismvotes.org “Health Care Reform: What does it mean for the Autism Community?”
Fully funded vs Self Funded

Fully funded policies

- Employer pays part or all of your premium
- Insurer pays claims from the pool of premiums
- Regulated by State law

Self funded (or “self-insured”) policies

- Employer collects or funds a pool of premiums
- Employer pays claims out of company assets
- Regulated by ERISA (not state law)
How can you know?

fully funded

self funded
How can you know?

- May not be clear from your insurance card
- Many employers use an insurance company as a third party administrator
- Contact your HR department
KS Autism Waiver
Overview

- Children diagnosed with ASD may enter the program prior to age 6
- Services are limited to 3 years and include
  - Qualified ABA providers who develop and implement the child’s Individual Behavioral Program/Plan of Care
  - Respite care
  - Parent Support and Training
KS Autism Waiver

Data

• Number of children served = 45
• Number of children on waiting list = 256
• Average cost per child per year = $16,000

reported by SRS Sept 2, 2011
KS Autism Waiver

Assessment

• estimated cost to eliminate the waiting list = $4,096,000

• Expanding the provisions of KSA 75-6524 would allow
  • 13% of children to move off the waiting list (i.e. those with fully funded health insurance), and
  • decrease the cost of eliminating the waiting list by $532,000
KS Autism Waiver

Recommended Action

• Appropriate funding to eliminate the Autism Waiver waiting list
• Expand the provisions of KSA 75-6524 beyond the SEHP effective July 2012 or sooner
KS Developmental Disability Waiver

Overview

• Serves children age 5 and older diagnosed with MR or DD

• Services include assisted services, day services, personal assistant services, residential supports, supported employment, family/individual supports
Total number of individuals served = 8,065
- 7,029 adults
- 1,036 children

Total number of individuals on waiting list = 4,668
- unserved: 3,047 (1,465 adults, 1,582 children)
- underserved: 1,621 (1,388 adults, 233 children)

reported by SRS Aug 5, 2011
KS Developmental Disability Waiver Assessment

- Estimated cost to eliminate the DD waiver waiting list
  - $182,549,282 (All funds)
  - $73,019,713 (State General Funds)
KS Developmental Disability Waiver

Recommended Action

- Appropriate funding to eliminate the DD Waiver waiting list
Combatting Autism Reauthorization Act (CARA)

- signed in to law by President Obama Sept 30, 2011

- Continues federal funding at current levels, i.e. $693 million, over the next three years dedicated exclusively for autism-related work by the NIH, CDC, and other federal agencies

- Kansas Leadership Education in Neurodevelopmental and Related Disabilities (LEND) Program.
  - Nine Graduate students
  - Two physicians per year
  - Outreach training to Special Education teams, Mental Health Centers, and community physicians
Contact Information

Autism Speaks, the world’s largest autism advocacy organization, is dedicated to increasing awareness of autism spectrum disorders, to funding research into autism, and to advocating for the needs of affected families.

For more information, please visit autismvotes.org

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