ADDITIONAL INFORMATION REQUEST BY SEN. DARRELL STEINBERG:

**SB 946 AUTISM INSURANCE MANDATE HEARING**

QUESTIONS TO THE ADVOCATES:

Information Received From Autism Society Of California:

**Families receiving Regional Center Families Receiving ABA (Behavioral Health Treatment) for Autism: Before SB 946 (7/1/12) vs. Now (2/7/14)**

1) The total number of individuals getting ABA has increased by 11,031 (from 19,559 to 30,590): **THIS IS AN INCREASE OF 56%**.

2) Health insurance funding has increased by **406%**. (From 3,452 to 17,480)

3) Regional Center funding has decreased by 3,917 (from 14,957 to 11,040). **THIS IS A DECREASE OF 35%**. In addition there are 1,840 in the process of applying for health insurance ABA treatment.

**Non-Regional Center Families Receiving ABA (Behavioral Health Treatment) for Autism: Before SB 946 (7/1/12) vs. Now (2/7/14)**

1) The total number of individuals getting ABA therapy has increased by **30%**. (the total numbers are estimated anywhere from 1,724 to 7,953 depending on the “model” utilized for these estimates.)

2) Health insurance funding has increased by **136%**. (The total numbers are estimated anywhere from 2,874 to 23,858 depending on the “model” utilized for these estimates.)
3) Private pay decreased by 250%. (The total numbers are estimated anywhere from 958 to 7,953 depending on the “model” utilized for these estimates.)

4) Early Start (Regional Center) families decreased by 399%. (The total numbers are estimated anywhere from 766 to 6,362 depending on the “model” utilized for these estimates.)

Information Received From Kristin Jacobson:

Regional Center Families receiving ABA (Behavioral Health Treatment) for Autism before SB 946 forced to drop insurance or drop/reduce ABA

1. Between 2,100 and 2,400 (14-16%) families were forced to discontinue or reduce ABA between July 2012 and February 2014. (Inability to afford co-pays/deductibles was the predominant cause listed.)
2. Between 2,200 and 2,800 families (15-19%) were forced to drop an individual from their health plan between July 2012 and February, 2014, most commonly due to the high cost of co-pays and deductibles. In these cases the regional center would be forced to pay the entire cost of ABA treatment instead of the co-pay or deductible (which is only 10-20% of the total).

Regional Center Families receiving ABA (Behavioral Health Treatment) for Autism before SB 946 (7/1/12) vs now (2/7/14)

1. The number for families getting ABA has increased by a range of from 4,219 to 4845 (from 19,559 to 23,778 or 22,561 to 27,306): THIS IS AN INCREASE OF 22%.
2. Health Insurance funding has increased by 320% (from 3,452 to 14,497 or 3,964 to 16,648).
3. Regional Center Funding has decreased by 3,917 (from 14,957 to 9,204 or 17176 to 10,570. THIS IS A DECREASE OF 38%.
Non-Regional Center families receiving ABA (behavioral Health treatment) for Autism before SB 946 (7/1/12) vs now (2/7/14)

1. The total number of individuals getting ABA therapy has increased by 17%. (The numbers are estimated anywhere from 1,751 to 3,449 to 7,953 depending on the “model” utilized for these estimates.)

2. Health Insurance funding has increased by 136% (the total numbers are estimated anywhere from 5,252 to 10,347 to 23,858 depending on the “model” utilized for these estimates.)

QUESTIONS TO DDS:

1) Of the **11,000** regional center (RC) consumers who received RC funding between July 1st to Dec. 31st of 2013, do we know how many of these had private insurance coverage?

   Response: **We do not collect private insurance coverage information** for all consumers. However, we do know that **1,627** consumers who are eligible for Medi-Cal also have private insurance coverage. Additionally, it might be reasonable to assume that a **high percentage of the 3,100 consumers** not eligible for Medi-Cal are covered by private insurance.

2) Of the **11,000** regional center (RC) consumers who received RC funding between July 1st to Dec. 31st of 2013, do we know how many received direct ABA services vs. the number who received funding for co-pays/co-insurance?

   Response: Data at this point shows that RCs funded **co-pays/co-insurance for 430 of the 11,000 (4%) consumers.** As mentioned in the hearing, due to the time needed to transition to uniform methods of identifying these payments, it is very likely this number underrepresents the number of consumers who have or will receive RC funding for co-pays/co-insurance. However, we will continue to work with ARCA and the regional centers to obtain complete information.
3) Of the **11,000** regional center (RC) consumers who received RC funding between July 1st to Dec. 31st of 2013 for co-pays/co-insurance, do we know the number of consumers who exceeded the 400% FPL and were funded through the “extraordinary exemption” clause?

Response: We are working with ARCA to get the number of consumers that had cop-pays/co-insurance funded through the exemption.

4) The number of consumers diagnosed with autism who received RC-funded behavior services in **fiscal year 11/12 was 14,955.**

QUESTIONS TO LAO:

a) The age breakdown for the **684** consumers with autism (but not on Medi-Cal) who were **no longer receiving ABA treatment** purchased by the RC in 2012-13—when compared to 2011-12:

   a. Response:
      
      306/684 (45%) were 0 to 6 years of age
      
      388/684 (55%) were 17 to 21 years of age

b) Of the **684** persons with autism no longer receiving ABA treatment purchased by Regional Centers how many

   a. Are now receiving that treatment from private insurance?

   b. Completed their treatment?

   c. Stopped receiving treatment before completion and are not now receiving it through a private insurer? (stopped getting ABA therapy entirely)

   d. Do we know how many individuals had private insurance coverage for SB 946 services but dropped the RC consumer from their coverage because of the cost associated with co-pays, co-insurance or deductibles?

Response to the above questions:
As we’ve discussed, DDS does not have information on the outcomes
for the 684 consumers with autism (not on Medi-Cal) who were no longer receiving ABA treatment purchased by the RC in 2012-13—when compared to 2011-12. Because the number of consumers with autism (not on Medi-Cal) receiving ABA treatment purchased by the RCs was increasing in the years prior to the autism insurance mandate, the assumption is that the drop of 684 consumers in 2012-13—when the autism insurance mandate went into effect—indicates that these individuals received ABA treatment through private health insurance. However, it is not clear exactly how many of the 684 individuals actually received ABA treatment from private health insurance, completed their treatment, stopped receiving treatment, or dropped their private insurance coverage for financial reasons.

c) Additional information from LAO:

a) The total number of RC consumers with autism on Medi-Cal from 2008-09 through 2012-13 has increased by 50%.

<table>
<thead>
<tr>
<th>Fiscal Year</th>
<th>2008-09</th>
<th>2009-10</th>
<th>2010-11</th>
<th>2011-12</th>
<th>2012-13</th>
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<tbody>
<tr>
<td>Consumers</td>
<td>6,148</td>
<td>6,649</td>
<td>7,326</td>
<td>8,243</td>
<td>9,229</td>
</tr>
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(The estimated cost for BHT/ABA services for current enrollees: $35-50 M.)

b) The total number of RC consumers with autism from 2008-09 through 2012-13:

The Department of Developmental Services has informed our office that this data request will take time to gather, as it needs to be submitted to the department’s IT Data Extraction unit.

INFORMATION FROM THE CALIFORNIA DEPT. OF INSURANCE (CDI):

a) During the calendar year 2012-13, CDI received 129 autism complaints, both for ABA and non-ABA treatments.

b) Of these 129 cases, 102, or 80% were resolved in favor of the insured consumer, either through the formal Independent Medical Review, or IMR, process, or via direct intervention by our Department of Insurance. There
are also a handful of cases still pending, so the 80% number could go up somewhat, pending final IMR results or results of our investigation.

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