'We Ain't Done Yet,' Steinberg Says at Legislative Hearing on Autism Coverage

by David Gorn Wednesday, March 5, 2014

At a state Senate hearing yesterday, autism advocates and state officials assessed gains and challenges of autism coverage in California over the past few years -- and came away with a long to-do list.

The informational hearing of the Senate Select Committee on Autism and Related Disorders was designed to evaluate the effect of state laws on autism services -- in particular SB 946 by State Senate President Pro Tempore Darrell Steinberg (D-Sacramento), which required private insurers to cover autism therapy.

"What we saw is that, on balance, SB 946 has been a tremendous success," Steinberg said. "We never rest on our laurels, we know there's more work to do. But success is exciting to lawmakers. It motivates us to want to do more."

Doing more would be welcome to autism advocates, who presented a long list of access concerns along with their praise for recent success.

The centerpiece of the hearing was a survey released yesterday by the Autism Society of California. It showed improved access to autism services because of SB 946 and pointed to problems with other new regulations governing state-contracted regional centers that provide autism services. The new rules shift payment of insurance co-pays and deductibles away from regional centers and onto families.

According to the survey, almost 20% of families receiving autism treatment at regional centers have cancelled the health insurance policies of their children, in large part because they can't afford the co-pays and deductibles.

"The co-pays and deductibles [rules] have been a serious and catastrophic obstacle for families," said Rick Rollens, a legislative adviser to ARCA, the Association of Regional Center Agencies. "Families are in a sort of 'Sophie's Choice' situation here. And who suffers? It's always the child."

Steinberg was surprised by a survey statistic that showed 57% of non-regional center families who are eligible for autism care did not apply for services.
"That's more than half!" Steinberg said. "We have to spread the word here."

"Many people are still under the impression that it's still not covered," said Kristin Jacobson, president of Autism Deserves Equal Coverage. "So we need to make sure insurers tell people this is a covered benefit and that [they] do have access to that benefit."

Sen. Mark Leno (D-San Francisco) focused on anecdotal reports that insurers may be delaying approval of autism care.

"What's the disincentive for them to be doing that?" Leno asked.

"There is not a disincentive, and that's the problem," Jacobson said. "If a denial is overturned in [an independent medical review], then there's a penalty, but there are relatively limited penalties."

"So if we're looking at amending SB 946," Leno said, "we'd want out-of-pocket costs to be paid by insurers [when a denial is overturned]. And maybe we put some kind of time frame on this, so if they've already gone past that timeline, it would cost them."

"There is precedent for a $5,000-a-day fine," which would likely dissuade unnecessary denials, Jacobson said.

Steinberg, toward the end of the hearing, brought up the biggest chip on the table: the possibility of making autism therapy a Medi-Cal benefit.

"The next step, of course, is extending (applied behavior analysis) therapy to families who are on Medi-Cal," Steinberg said. "It's equal protection. If it's good for some kids, then why isn't it good for all kids?"

Steinberg answered his own question.

"It's an issue of money, and we intend to take that up during the budget session," Steinberg said. "We ain't done yet. There's one more budget cycle."