

# Using Speech

## Slow Moving in a Progressive State

By Robin Springer

California is supposed to be the progressive state. Named after a mythical paradise, we even have a city that legally changed the title "pet owner" to "pet guardian." While our progressive status may apply to our four-legged friends, it may not extend to all Californians, specifically Medi-Cal recipients who require Augmentative and Alternative Communication Devices (AAC) to communicate.

Medi-Cal, California's Medicare program, is a federal health insurance that covers nearly seven million Californians who are 65 years or older or who are younger than 65 years and are disabled. In 2003-2004, Medi-Cal spending was estimated at \$29.2 billion. In 2004-2005 it is expected to approach \$33 billion.

Medicare uses the term Speech Generating Device (SGD) to describe AAC, products that provide voices to individuals who physiologically cannot speak. Typical SGD users include those with Cerebral Palsy, Amyotrophic Lateral Sclerosis (ALS or Lou Gehrig's disease), Multiple Sclerosis, Parkinson's Disease, Brain Stem Stroke, and Traumatic Brain Injury.

Medi-Cal reimbursed SGDs at MSRP until November 1, 2003 when the rate dropped to 80 percent of MSRP. On November 1, 2004 the rate dropped further, reimbursing 80 percent of the Medi-Cal Allowable Rate. A product that lists for and was originally reimbursed at \$2,795 was reimbursed at \$2,236 after November 1, 2003 and reimbursed at \$1,677 after November 1, 2004.

This new Medi-Cal fee schedule is less than the cost of manufacturing the device, prompting manufacturers to stop shipping to California.

Manufacturers argue the embargo is necessary because, in addition to primary manufacturing costs, the price of SGDs includes free technical support for the life of the product, sometimes six years or longer.

Lewis Golinker of the Assistive Technology Law Center estimates that approximately 150 Medi-Cal recipients are approved for SGDs each year. "In our wildest estimates Medi-Cal is saving \$100,000 annually by cutting funding for these devices." For perspective, \$100,000 of \$33 billion is .000003 percent.

*"With the device he teaches art, consults, ...and travels the country as a public speaker."*

Those close to the process in Sacramento say that when the legislature, in conjunction with Governor Davis, implemented the cuts, "there may have been discussion as to the number of SGDs provided by Medi-Cal, but no feasibility studies were done to determine the cost impact in dollars or human suffering."

Individuals with profound disabilities will always be consumers, but when given tools to be productive, they can give back to the community as well. Using SGDs can enable users to pursue an education, to work, to learn and teach. Imagine buying a movie ticket or ordering a pizza without speaking or writing. Without these devices, tasks of daily living that should be mundane become overwhelming burdens.

Rick Hohn was unable to work until he got his SGD. With the device he teaches art, consults for DynaVox Technologies, and travels the country as a public speaker. He also pays taxes.

This would not have been possible without his SGD.

In 2004, Californians who were approved for SGDs but were not able to receive devices, filed litigation, which settled in October 2004, raising the payment rate to 99 - 100 percent of the Medi-Cal fee schedule. The November 2004 rate reduction decreased payment rates beyond the rates that necessitated the litigation. Manufacturers stopped shipping to California again.

When similar cuts were attempted in Georgia, constituents started a grassroots campaign, successfully preventing implementation. Attorneys are attempting a resolution with Medi-Cal and hope to avoid additional litigation. In the interim, lobbyists have introduced Assembly Bill 436 (AB436), which restores reimbursement rates to those agreed upon in the October 2004 settlement.

AB436 is expected to pass a vote on the Assembly floor as this column goes to print. If there are no obstacles, it should make it through the Senate before summer, after which it will end up on Governor Schwarzenegger's desk, to be signed into law or vetoed. Stan Rosenstein, deputy director, medical care services, Department of Health Services, who may advise the Governor, says his department does not have a position on AB436, pending an internal investigation.

Approximately 40 Californians have been approved for SGDs this year, but they are not able to receive devices. If you are a Californian, let Governor Schwarzenegger know what you think ([www.govmail.ca.gov/](http://www.govmail.ca.gov/)). Community involvement worked in Georgia. It can work in California. We are the progressive state, aren't we?



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