

A friend in need

Students pen pleas to help disabled boy

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SANTA CRUZ — It was their turn to tell Gov. Pete Wilson how government should work.

And local students told him, in more than 500 letters, exactly what was wrong with a government that has let down a friend.

Hundreds of students rallied on behalf of Jesse Houts last week, penning pleas to enable their friend to live at home and remain in school.

They hope to reverse a decision by California Children's Services to cut funds for home health care at the end of the year.

Without approximately \$100,000 per year in state funding, the 16-year-old Harbor High junior could be institutionalized, according to his mother, Nancy Houts.

To keep that from happening, students at Harbor High School took turns at a letter-writing table.

By Friday afternoon, they'd written 509 letters, said Anne Scott, a resource specialist at the school, who initiated the letter campaign.

Letters were written, too, by students at Gault Elementary and Branciforte Junior High, both schools that Houts attended.

While his friends at Harbor wrote, Houts sat in his motorized "assault vehicle" wheelchair and organized the music that blasted over the campus. He said he was somewhat "surprised" by the effort and the "really, really nice things they said about me."

In most ways, the blue-eyed, freckle-faced Houts is a typical teen. His wheelchair is emblazoned with stickers of musical groups: The Cramps, Bones, Adult House and Jane's Addiction.

He's a movie buff, computer ace, game wizard and political activist. He takes Algebra II, biology, economics, English and Spanish 3 classes. He just finished reading "Catch 22."

He plans to go to college and become a film director. He produced his first video at age 11.

But Houts is also very special, disabled since birth with a rare form of congenital muscular dystrophy. He uses a ventilator to help him breathe and needs to have someone with him at all times.

His condition is not getting worse, but he is more susceptible to illnesses, according to his mother, Nancy Houts. He has been near death several times.

The youth's age has placed him in a funding gap between government agencies. Until his family's insurance benefits were



Shmuel Thaler/Sentinel

Jesse Houts wants to live at home and remain at Harbor High — if state will let him.

exhausted in October 1990, his in-home care was paid for by private health insurance.

At that time, California Children's Services authorized an exception to their regular benefits and agreed to pay for in-home nursing services for one year with renewal subject to approval.

Approval was denied last October. Houts will not be eligible for Medi-Cal until age 18, 15 months from now, when he may qualify for an in-home medical waiver to pay for nursing care.

Qualifying for that will be another battle in which the Houts family has to prove it is cost-effective and appropriate to have the youth at home.

Similar Medical waivers have been granted to for several other Santa Cruz youth: Chipppo Ramirez and Taylor and Shelby Zak.

Jesse's mother, a Santa Cruz County foster-care social worker,

and father, Steven Houts, who works for the Santa Cruz County Parks and Recreation Department, are asking that California Children's Services continue funding in-home care until Jesse is 18.

The issue will be reconsidered at a hearing in Campbell Dec. 18.

His mother maintains that Jesse's home-care costs \$90,000 to \$100,000 a year. In a hospital, it would cost \$50,000 a month, she said.

A convalescent home, if one could be found to take her son, would cost about 10 percent less than home care, she says.

But, the Houts say, it's not just the money. They don't want Jesse to leave home, and they doubt anything less than around-the-clock care will be adequate.

"What if a tube comes off (his ventilator)?" she asks. "That happens, like two to three times a week."

Technology-dependent people like Jesse should have the same choice of where to live as anyone, said his mother. "The way it is now, it's blaming the victim like it's the disabled person's fault they cost money."

The way she sees it, "Jesse has given more than he's taken, by far. Anyone who knows him would agree."

His friends did agree, by the hundreds.

"Jesse has a lot of special gifts we don't want to lose," wrote Kristin Rock, a student at Gault Elementary, in an appeal to state officials. "His care may be a lot of money, but he is very special."

Another young friend and neighbor, Buck Noe, 10, wrote, "Jesse Houts is one of my best friends. I spend the night at his house. We play video games. We go to the mall. Please don't make my friend fade away."