Del. disability services are taken to task
UD professor presents plan to change budgeting

BY BETH MILLER
THE NEWS JOURNAL
01/27/2006

DOVER -- A nurse with a strong work ethic is worth a day in the life of Lea Castelli, 42, of Middletown. Castelli, who has multiple sclerosis, has to stay in bed all day if her aide doesn’t feel like helping her out of it.

And a transportation service that shapes its schedule to its passengers instead of forcing them to adapt to the service’s shifting schedule means Castelli can keep her appointments instead of canceling them at the last minute.

Steven M. Eidelman believes Castelli and others with disabilities should be able to choose the attendants and services that work best for them, instead of having to choose from a limited menu of state-run programs and institutions.

To do it, Eidelman -- a Delaware resident for two weeks and a University of Delaware professor since September -- would freeze the budgets of every agency that gets money to support those with disabilities. Then he would steer the agency’s new money each year in a different direction so more goes to people, and less goes to buildings and programs.

Bold plan from new transplant

Eidelman is new to the Delaware community, but not the disabilities community. For the past six years, he was executive director of the Arc of the United States, one of the most effective advocates for those with disabilities during the past 50 years. Last year, he was named UD’s Robert Edelsohn Professor for developmental disabilities.

Thursday, he was the keynote speaker at the eighth annual Life Conference, the state’s largest disabilities conference of the year. His budget suggestion would mean the demise of some programs, but a greater chance for people who now are limited by institutional and financial constraints to thrive, he said. Market pressure from those with disabilities and their families would determine what survives.

"The agencies that are responsive will thrive, and the others will go away," he said.

Shifting money to people instead of programs is a common concept in Delaware’s education circles, where the state allocates a certain amount of money for every public school student. That money follows them to whichever public school they enroll in.

State says it’s already moving that way

Eidelman said it could take three years to seven years to make the transition work for those with disabilities. He urged those with disabilities, their families and advocates to do a better job of making their needs known to legislators and not giving up. Change is necessary, but difficult for those who helped build the system now in place, he said.

"Can the Delaware state government be trusted to come up with a better solution?" he said.

The "money-follows-the-person" approach is already gaining ground in Delaware, said Marianne Smith, director of the state Division of Developmental Disabilities Services. She said when Eidelman gets to know the state better, he will see that it is ahead of the curve on this issue.

"We are moving in the direction he talked about being so important -- self-direction," Smith said. "We have partnerships, and we are working together to move the system from a really old model to a new way."
Contact Beth Miller at 324-2784 or bmiller@delawareonline.com.