Advocates for Iowans with brain injuries have prepared a federal civil rights lawsuit to try to force the state to provide better services.

The advocates haven’t decided whether to file the lawsuit, but they say the state is violating a landmark U.S. Supreme Court decision declaring that disabled Americans have a right to live outside institutions if they’re capable of doing so. Too many of Iowa’s 95,000 brain-injured people wind up in nursing homes, jails or psychiatric wards because they lack services that would help them live in their homes or in small group homes, the advocates say.

Iowa officials say they’re making a good-faith effort to improve, noting that state leaders are discussing major reforms in the mental health system.

Geoffrey Lauer, executive director of the Brain Injury Association of Iowa, said state leaders promised in 2005 to substantially improve services by 2009. “It hasn’t happened,” he said.

Now, he said, legislators have either dropped or delayed improvements that a brain injury task force suggested for the pending overhaul of the state’s mental health system.

“It sounds like the same old thing,” he said, noting widespread doubts about whether legislators will approve enough money for the overall mental health effort.

Lauer noted that improved medical care after accidents or strokes means more people are surviving brain injuries but need long-term support. He said his group has suggested ways to pay the several million dollars a year it would cost to start improving brain injury services.
For example, he said, since many brain injuries are caused by traffic accidents, the state could impose a surcharge on vehicle registration fees or on driver's license reinstatement fees for people convicted of drunken driving.

Lauer said hundreds of Iowans with brain injuries who now live in nursing homes could live at home or in small group homes if they had sufficient assistance with everyday needs. Forcing them to stay in institutions violates a 1999 Supreme Court ruling, known as the Olmstead decision, he said. In many cases, he said, the switch could save money for the state Medicaid program, which now is willing to spend more per day on nursing home care than it spends on in-home care.

The 27-page Iowa lawsuit would be modeled on one filed in Massachusetts in 2007 by that state's brain injury association. Massachusetts government leaders settled that lawsuit in 2008 by agreeing to help hundreds of people with brain injuries move out of nursing homes and into community settings.

Arlene Korab, executive director of the Brain Injury Association of Massachusetts, said leaders of her state initially contended that the lawsuit was unnecessary because they already were trying to help.

"But they weren't doing the best they could," she said. "We thought they could do better."

The settlement guarantees that Massachusetts won't have to spend more per person in the community than it spends serving people in nursing homes. Also, the shift is being made fairly gradually, with about 120 people having moved out of nursing homes or being approved for such moves so far.

Iowa Rep. Renee Schulte, a Cedar Rapids Republican helping lead mental health discussions, said she was disappointed to hear that the brain injury group has raised the possibility of a federal lawsuit before legislators have finished work on the current reform bill.

“It doesn’t make much sense to be talking about it today,” Schulte said of the possible lawsuit.

Sen. Jack Hatch, a Des Moines Democrat who also is helping lead the discussion, agreed with Schulte that the state is making serious efforts to help people with mental
disabilities, including those with brain injuries. He noted, for example, that brain injury representatives would be included in new regional mental health authorities.

However, he said he respected the right of advocacy groups to press their cases in court if they are unsatisfied with progress in the Legislature.

Chuck Palmer, director of the Iowa Department of Human Services, said the brain injury patient advocates were given a fair chance to express their priorities during discussions of the mental health reform plan. He acknowledged that the current bill says new services would be added "subject to the availability of funding," but said the state already has taken steps to help.

Palmer noted that the Legislature is spending $5 million this fiscal year to pare waiting lists for services, including by brain injury patients, and plans to spend another $5 million next year. His spokesman said the wait for those people has been cut from 18 months to less than eight months.

Nancy Hale, executive director of the state chapter of the National Alliance on Mental Illness, said her group had no plans to join a lawsuit against the state. She said patient advocates should give legislators space to work.

“I think they really are making a concerted effort to get the redesign done," she said.