

# Make Iowa the No. 1 state for disability services

Pay workers better, and ensure care is provided in home and community settings.

The recent heart-rending story in the Des Moines Register about Nicole and Joe Paulsen and their struggles with Joe's disability should prompt Iowa to finally abide by the Americans With Disabilities Act, and subsequent Supreme Court decisions.

One of the four goals of the Americans with Disabilities Act, as stated in the act, is "independent living." As the lead sponsor of the ADA in the Senate, and with Sen. Lowell Weicker one of the drafters of the initial bill in 1988, and as chairman of the disability policy subcommittee, I held numerous hearings over several years documenting the plight of disabled persons stuck in institutions or nursing homes. We heard the cry of so many who wanted to "live in our home, not the nursing home." We

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also documented that not only was it better and more supportive of individual rights and freedom for the disabled to live in their community with supportive care, but it was also cheaper for the taxpayers!

Following passage of the ADA in 1990, the U.S. Supreme Court in the Olmstead case in 1999 held that states cannot put persons with disabilities in institutions as a condition for publicly funded health coverage. Instead, states must direct their programs to community-based care for the disabled.

It has been 32 years since ADA was signed into law, and 23 years since the Supreme Court decision, yet Iowa still does not meet the requirements of ADA or the Olmstead decision. This is shameful!

The US Department of Justice — under President Donald Trump, I might add — investigated Iowa's support regime for persons with intellectual and/or developmental disabilities, or IDD, and issued a stinging assessment of Iowa's failure to abide by the ADA. Here is the final sentence in the DOJ summary: "In sum, Iowa's system of care requires people with IDD to live in segregated facilities to receive the services they need and for which they are eligible under Medicaid. This segregation is unnecessary and violates the ADA." The DOJ report pointed out that nationally, the number of people with disabilities living in institutions has dropped by half since passage of the ADA. However Iowans with disabilities living in institutions has stayed the same since 1982!

The report also says that lack of quality care for persons with IDD is due partly to poor pay. A 2020 survey showed the average hourly pay for a qualified direct care worker in a community/home setting was just \$11.98 an hour.

By contrast, a worker at the Wood-ward institution starting wage was \$17.96 per hour.

The report points out that the state could save money by getting people out of institutions, nursing homes, and intermediate care facilities. As we found out during our committee hearings years ago, at any level of care for a person with IDD it is cheaper for home and community based services.

Two issues linger. One, many Iowa families have previously had bad experiences with in-home services being cut back periodically, resulting in traumatic removal of a family member to a nursing home or institution, and sometimes involving the police or other law-enforcement personnel. I suggest that Iowa pass an overarching mandate, similar to ADA, that secures the right of any Iowan who qualifies for institutional care under Medicaid to receive those services in a home or community-based setting. An independent agency, such as Disability Rights

Iowa, would be the arbiter of any dispute between the individual or the caregiver, and the state regarding quality

of care and any proposed extension or curtailment of services.

The second lingering issue: Does Iowa have the “resources,” i.e., money, to afford this? First of all, the federal law is quite clear: if a person qualifies for institutional care under Medicaid, Medicaid must provide those services, and the state must pay its share of the Medicaid bill. Since it has been shown that home and community-based care is actually cheaper, then this should be no problem. Furthermore, haven’t I just read that the Iowa Legislature is passing a tax cut for all Iowans? It will save the average Iowa taxpayer \$1,300 per year?

And I hear that the “median” Iowan making \$68,000 per year will see a tax savings of \$593 per year, and an Iowan making \$1 million per year will have a tax savings of \$66,879 per year?

Here’s a modest proposal: Figure out how much it will cost the state to pay a starting wage of \$25 per hour to a home care service provider for a qualified person with a disability, including retirement benefits, sick leave, parental leave, paid vacations, etc.

Also, add an annual inflation adjustment to the starting wage. Then calculate how much of this “tax cut” would have to be rescinded to pay for such an “Iowa Disability Care” system. I will bet that “median” Iowans would be happy to give up some of their \$50-per-month tax savings to support such a decent, humane, system.

I would further bet that the highest-income Iowans would also be happy to give up some of their \$5,500-per-month tax savings for this “Iowa Disability Care” system.

The story about Nicole and Joe Paulsen should also give us pause to consider what is happening to us. I mean what is happening to us as Iowans if collectively we won’t meet our legal — and, I submit, our moral — obligation to care for those who were born with or acquired a disability through accident or health, like Joe Paulsen? Do we just “care” but not if it costs us some of our tax “savings?”

Some have a goal of making Iowa an “income tax free” state.

I propose a different goal: Let’s make Iowa number one in the nation in our home and community based services for people with disabilities. Now that would be real bragging rights!

*Tom Harkin represented Iowa in the U.S. Senate from 1985 to 2015.*

**Joe Paulsen stands with the assistance of his wife, Nicole, at their apartment Feb. 22 in Johnston. Joe is in his late 30s, and was severely disabled by a benign brain tumor and several strokes a few years ago. The couple qualify for state-financed care to help Joe remain at home instead of being placed in a facility. However, they struggle to find anyone who will accept the pay rates offered under Iowa’s Medicaid program. MEG MCLAUGHLIN/THE REGISTER**