

## Give Voice to the Voiceless - Families Support Family Care and IRIS

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***This week Senator Kathleen Vinehout writes about the advocacy of hundreds of Wisconsin citizens in support of Family Care and the IRIS programs. Gov. Walker's budget proposes significant changes to these programs and the adverse impacts of the changes were shared in personal stories from people all over the state.***

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MADISON - I remember when I first met a man I'll call 'Ron'. He came to my office with his caregiver. He couldn't speak but used a speech synthesizer and an iPad to introduce himself. He was joined by several friends – all in wheelchairs – who told me their inspiring stories of independence.

Ron passionately detailed how his caregiver assisted him with everyday activities we take for granted. He wanted me to work for funding so he could pay his caregiver a living wage. Wages for care workers are very low and have been for years.

Fast-forward a few years. Ron and his friends joined hundreds of citizens in the Capitol to advocate for critical long-term care programs. Many of the visitors had never been the Capitol and never met with a legislator. These citizen lobbyists were advocating for programs that provide them or their family member with health and independence.

The governor's budget proposal would likely turn Wisconsin's Family Care system over to a large for-profit insurance company in a no-bid contract. Wisconsin's IRIS program would be eliminated. Opponents are concerned the insurance company would deny services and eliminate caregivers.

Parents, family members, caregivers, neighbors and participants in the Family Care and IRIS programs called on legislators to stop the governor's proposed changes. These people gave a strong voice to the often voiceless participants in the long-term care portion of the state's Medicaid program.

Family Care is organized around regional non-profit Medical Care Organizations (MCOs) that oversee services for over 40,000 frail elderly, developmentally and physically disabled. In 2011 the Legislative Audit Bureau reported that nearly 60% of Family Care participants were able to stay in their own homes. IRIS is a fee-for-service option that establishes a small budget participants can self-direct to certain services and caregivers. Another 11,000 people use this option. Without these services most people would be forced to reside in expensive institutions.

Instead many individuals live more independently in Group Homes. An owner of a Black River Falls group home recently contacted me. She was forced to close one home because of previous budget cuts. She now worries about the other home she and her dairy farm family operates.

*"I am scared for our disabled and mentally ill people, and I don't want to see the MCO's go away. They provide such wonderful care for these people! The teams I work with are amazing people, and they sincerely care about these clients, it's not just a job. Several of the team members have given me their cell phone numbers in case of issues outside of business hours, they do not get paid for this. Please help keep these MCO's intact: the people need them."*

Family situations are all unique. The self-directed IRIS program allows flexibility in services based on those unique circumstances. I was contacted by an Eau Claire County couple who maintain their independence with the help of IRIS. The husband is a Gulf War vet; his wife of 16 years has severe disabilities because of a brain tumor.

*"If IRIS loses funding, Karen and I will be separated, her to a nursing home and me out of a job and homeless. Can you help us please?"*

Tammy McKelvie recently shared with me how IRIS changed her son Noah's life and "gave him

a voice." IRIS allowed her son to live independently despite the fact he needs constant care.

*"Noah may never reach the level of independence most people strive for but at least let him have choices over the parts of his life he can control. Let him be the architect to design blueprints to create a life of meaning."*

*"As human beings, none of us are totally independent. In some ways we are all interdependent upon each other and that is how it should be because we all live in society together."*

Indeed. As Hubert Humphrey so eloquently said, *"It was once said that the moral test of government is how that government treats those who are in the dawn of life, the children; those who are in the twilight of life, the elderly; and those who are in the shadows of life, the sick, the needy and the handicapped."*

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