



Julie Burish, Brookfield, 262-784-9627, jaburish29@gmail.com
Nancy Gapinski, Glendale, 414-335-8219, Nancy.Gapinski@gmail.com
Marion Holmberg, Waukesha, 262-527-4375, marionholmberg@hotmail.com

March 7, 2016

Testimony regarding the Family Care/IRIS 2.0 Concept Paper

Good afternoon. I am Nancy Gapinski and this is Julie Burish and Marion Holmberg. We are part of the Save IRIS leadership team, as well as, family members of IRIS participants. We would like to thank the Department for all of your efforts in the development of this Concept Paper. We are especially grateful to have been invited to meet with DHS to offer input from the perspective of IRIS participants and their families and pleased to see the positive results of this collaboration evidenced in the Paper. Thank you for your continued commitment to personal choice, person-centered planning, and cultural competence. We want to use this opportunity to share suggestions we have for the Self-direction section of the Concept Paper.

We started Save IRIS to preserve self-direction and we still feel it is at risk. Self-direction as it exists in the current IRIS program opens the door for participants to lead fully self-directed lives in the community. Over 12,000 people in Wisconsin choose full self-direction and many others choose to partially self-direct. Thousands of IRIS participants, their families, and workers asked the legislature to save IRIS and they responded with a commitment to preserve self-direction as it is experienced under the current IRIS program. We worry that the Concept Paper is not clear enough in that aspect and will lead to a more medical, managed care model that will change things dramatically.

Managed care is based on very different operating principles than self-direction. Safeguards are needed to ensure that managed care is not promoted above self-direction. We recommend that all self-direction consultation services be provided by independent ICAs. To ensure true choice and to avoid conflict of interest, each IHA should contract with a minimum of 2 independent ICAs who have completed the Wisconsin certification process. Self-direction Consultation is currently a Home & Community Based waiver service. In order to comply with CMS Conflict Free Case Management Rule, IHAs must not provide self-direction consultation services in-house.

Full budget and full employer authority for approved long-term care services is imperative to true self-direction and should be detailed in the concept paper.

- Self-direction must be available to ALL people eligible for long-term care services including those with complex/high cost care needs regardless of their guardianship status.
- We are concerned that the Concept Paper proposes a new method of setting individual self-direction budgets that is quite different and potentially less flexible than the current process. Currently IRIS participants get their overall budget first and then develop their plan knowing how much money they have to work with. The Concept Paper proposes to do the plan first and get the budget later.

"Save IRIS, Wisconsin's Self Direction Advocates" is a non-partisan association of IRIS participants and their allies dedicated to promoting self-direction in Wisconsin.



www.saveiris.org



Julie Burish, Brookfield, 262-784-9627, jaburish29@gmail.com
Nancy Gapinski, Glendale, 414-335-8219, Nancy.Gapinski@gmail.com
Marion Holmberg, Waukesha, 262-527-4375, marionholmberg@hotmail.com

- Individual budgets must be based on the participant's assessed support needs, determined through an objective and consistent tool that is used by all IHAs, and must support an individual's long term care goals. This includes full community access & integrated employment. Budgets should be based on the actual cost of services the person needs and not be reduced because natural supports are in place.
- DHS must develop, maintain and monitor the budget determination tool to ensure that participants have access to a consistent and adequate budget regardless of which IHA they choose. We recommend that DHS build upon the current budget determination tool to maintain consistency and continuity for participants.
- All participants should have the ability to hire the people they choose (who they feel are the most qualified & with whom they feel safe), including family members and independent care providers.
- We recommend the addition of "customized goods and services" to the Addendum 1 Benefit Chart, because this service is vital to meeting participant outcomes. This is a service currently included in IRIS and therefore should be included in the new system.

The people of Wisconsin have spoken and we value self-direction. We respectfully request these changes to ensure that true self-direction is preserved and promoted in Family Care/IRIS 2.0. We look forward to our continued collaboration with you in this effort.

Respectfully,

Julie Burish, Nancy Gapinski, and Marion Holmberg
Save IRIS

"Save IRIS, Wisconsin's Self Direction Advocates" is a non-partisan association of IRIS participants and their allies dedicated to promoting self-direction in Wisconsin.



www.saveiris.org