



Survival Coalition

of Wisconsin Disability Organizations

P.O. Box 7222, Madison, Wisconsin 53707

10/18/16

Survival Coalition is comprised of more than 30 statewide disability organizations that advocate and support policies and practices that lead to the full inclusion, participation, and contribution of people living with disability.

Survival Coalition Recommendations for the Proposed IRIS 40 Hour Rule

- Health and safety policies must be developed in concert with knowledgeable stakeholders including: persons with disabilities who receive care or have difficulty finding care providers; families who have been providing more than 40 hours of care in a week; representatives of personal care/home health agencies that have designed similar policies; representatives from IRIS Consultant Agencies; members of the IRIS advisory committee; advocates for people with disabilities.
- Health and safety policies should be decoupled from overtime rules and related considerations. Policies developed in response to Fair Labor Standards Act wage and hour rules and fiscal considerations may not necessarily align with health and safety assurance.
- Frequent changes to policies may present violations of due process. Potential issues with due process should be taken into consideration, and advocates working to protect due process rights (ombudsman programs and IRIS Advisory Committee) should be involved with the discussion prior to the changes being determined.

Priority Considerations

- People who have experienced previous abuse and neglect may need special considerations regarding number of care providers in the home. The individuals with disabilities and their families may have lingering fears about the safety of the person being served as well as concerns about safety of personal property and medications. These fears should not be dismissed and should be part of the problem solving conversation.
- While hours of work may be one factor in determining health and safety, any hour limitation should be informed by data on worker fatigue. For example, Wisconsin

administration code allows private duty nurses to work 12 hour shifts and 60 hour weeks. Presumably these parameters were informed by data that can be useful in designing future health and safety policies.

- Care providers are often in the best position to understand the needs and desires of individuals with disabilities. The balance of determining when an actual health and safety issue might be present while avoiding making assumptions about the family's interests is difficult to find.
- There is no one test for health and safety that can be applied across all situations. Long-term care program participants are individuals with unique lives and circumstances. Arbitrary limits on hours without a full understanding of the challenges faced by individuals and families do not increase health and safety, especially in consideration of the increasing loss of a high quality workforce. On the other hand, care provider fatigue, the need for external eyes in some cases, and vigilance in protecting individuals with disabilities are all important concerns. What are safe circumstances for one individual may be a situation that requires additional scrutiny to ensure health and safety for another individual.
- Program participants need clear policies around health and safety with adequate information and support to understand how to comply. Those clear policies should be limited to an examination of protecting the health and safety of the individual with disabilities and finding ways to do so.
- There can be a variety of creative solutions to address health and safety concerns. Strategies and suggestions should be compiled in an easy-to-use format for consultants and care providers to consider when there are concerns.
- The correlation between increasing the number of care providers and increased health and safety has not been established. What has been established is that increased connection to a community of people who know and recognize the individual—does increase health and safety. Finding more ways to create meaningful connections with the larger community should be a priority in service planning.
- IRIS consultants and other service providers need to be fully supported to understand required health and safety policies in order to be prepared to adequately explain them to participants. This explanation needs to take the tone of concern for the individual with disabilities and must be presented in a nonjudgmental way, respecting the efforts and concerns of the family. Because of the complexity of planning for health and safety issues, there needs to be an understanding that a one-time enrollee education sheet will not suffice. The conversation needs to be planned, respectful, and ongoing.
- Unpaid supports provided to an individual must be provided of free will by the support person and only in the amount which the person is willing to provide. Ultimately, health and safety may be compromised if supports are forced or mandated.
- Health and Safety policies must be flexible enough to recognize care provider shortages throughout the state. The shortages result in care providers spending

inordinate amounts of time seeking and training workers. The difficulty in working with this problem increases stress on the participant and/or family.

In summary, Survival Coalition strongly encourages DHS to put the proposed 40 Hour Policy on hold until concerns and recommendations are discussed with stakeholders and real health and safety policies can be further addressed, not just a limiting of hours.

Survival Co-Chairs:

Maureen Ryan, moryan@charter.net; (608) 444-3842;
Beth Swedeen, beth.swedeen@wisconsin.gov; (608) 266-1166;
Kristin M. Kerschensteiner, kitk@drwi.org; (608) 267-0214

Survival Coalition Issue Teams: education, employment, housing, long term care for adults, long term care for children, mental health, transportation, workforce, voting, Medicaid and health care.

Real Lives, Real Work, Real Smart, Wisconsin
Investing in People with Disabilities