



of Wisconsin Disability Organizations

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January 7, 2014

The Honorable Kathleen Sebelius  
Secretary US Department of Health and Human Services  
200 Independence Ave., SW  
Washington, DC 20201

Dear Secretary Sebelius,

The Wisconsin Survival Coalition is writing to voice its support for the proposed national standards for Home and Community Based Services (HCBS) as contained in proposed rule 26379, which amends regulations for Section 1915(c) and Section 1915(i) of the Social Security Act.

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 supports CMS adopting language into the regulations that “home and community-based settings do not include nursing facilities, institutions for mental diseases, intermediate care facilities for the mentally retarded, hospitals, or any other locations that have the qualities that have the qualities of an institutional setting as determined by the Secretary.” The proposed rule also outlines qualities that home and community based settings must exhibit, including being integrated into the community, supporting independence, involving individual choice, and protecting individuals from coercion and restraint.

Survival Coalition views these proposed language changes to the regulations as particularly positive steps to improve the lives of people with disabilities, and believes this proposed federal rule change will support Wisconsin in changing an over-reliance on segregated settings for individuals with disabilities.

In Wisconsin, the continuing expansion of Family Care/IRIS HCBS waivers—now operating in 57 out of Wisconsin’s 72 counties—entitles individuals to an array of long term supports including community, integrated residential and employment supports. A majority of the state’s eligible residents have access to this set of services.

A November 2013 report to the state legislature’s Joint Finance Committee from the state Department of Health Services (DHS) provided a status and assessment of publically-funded community-based long-term care in Wisconsin. Wisconsin’s Family Care and IRIS program—the self-directed alternative to managed care seek to maintain people’s independence, community connections, and delay the need for intensive and expensive long-term care services.

The proposed changes to the federal rule will compliment and encourage additional progress on the ongoing efforts Wisconsin has made over the past three decades to transform the long-term care system from one dominated by institutional care in nursing homes to one where people with long-term care needs have the opportunity to receive less intensive and less expensive services in their homes and community based settings.

The proposed rule language clearly supports Wisconsin's movement toward a system where all residents are entitled to long-term care services in their own homes and communities, are supported to maintain as much independence as possible, and if long-term care outcomes cannot be supported in the home that care is provided in least restrictive residential setting possible as a first option.

Changes to the federal rule can also prompt needed improvements and prioritization of integrated employment for people with disabilities in Wisconsin. While employment supports are among the entitlements in Family Care/IRIS, as of April 2013 only 8% of the nearly 28,000 working-age individuals enrolled in these long-term care programs were working in integrated employment settings, while more than 19% were working in fully Medicaid funded segregated employment facilities. In the last five years, there has been a 23% ground in the number of Wisconsin HCBS waiver participants being placed and funded in segregated day service facilities.

In its November 2013 report to the legislature, DHS identified employment for young adults with disabilities as "essential to the fiscal viability of long-term care," and prioritizing integrated employment for young adults "results in these members having more personal income and resources to support their ability to live in their own homes in the future."

Survival Coalition supports these proposed rule changes. We find them to be consistent with the goals of individuals with disabilities who seek to live, work, and participate fully in community life in the most integrated settings.

Sincerely,

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CC. Sen. Tammy Baldwin, Sen. Ron Johnson,  
Rep. Paul Ryan, Rep. Mark Pocan, Rep. Ron Kind, Rep. Gwen Moore, Rep. James Sensenbrenner,  
Rep. Tom Petri, Rep. Sean Duffy, Rep. Reid Ribble

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*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.*

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Investing in People with Disabilities