



Survival Coalition

of Wisconsin Disability Organizations

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July 17, 2009

Senator Russ Feingold
Senate Office Building
Rm. 506 Hart
Washington, DC 20510

Subject: Health Care Reform Issues specific to People with Disabilities

Dear Senator Feingold:

We are writing on behalf of the Survival Coalition of Wisconsin Disability Organizations, the largest disability coalition in Wisconsin, and the over 1 million people in Wisconsin who self-identify as having some form of mental or physical disability (a list of Survival Coalition member organizations is attached). Lack of health insurance or problems with health insurance are two of the most serious problems facing people with disabilities, their families, and their provider agencies.

Here are some of the major problems specific to the disability community:

1. Some families of children with disabilities a) have no health insurance, b) have coverage which excludes their child with a disability because of the child's "pre-existing condition" (i.e. his/her disability), or c) have coverage that is not comprehensive (e.g. it does not include vision care, dental care, rehabilitation services, occupational therapy, physical therapy, autism treatment, hearing aids, or cochlear implants).
2. Some adults with disabilities are not eligible for Medicaid. A notable example are the people whose work histories have resulted in them receiving slightly too much Social Security Disability Income (e.g. \$1400/month) to meet the income limits for Medicaid. Some of these people have severe disabilities and complex medical problems, and incur major medical bills.
3. Many people with disabilities who are on Medicaid are afraid to accept a job because the employer does not provide health insurance and the wages would not be sufficient to pay for their health care out-of-pocket.

4. Many people on Medicaid cannot find primary, acute or specialty providers who will accept their Medicaid card because of inadequate Medicaid rates.
5. For many people with certain disabilities (e.g. diabetes, ALS, muscular dystrophy, multiple sclerosis), their highest priority in health care is chronic disease management. Unfortunately, many health insurance plans do not provide that.
6. There are over 75,000 direct care workers for people with disabilities and elderly people in Wisconsin. Approximately a quarter of these workers have no health insurance at all. Of the ones who do have coverage, the employee premium cost-share, co-pays and deductibles are often prohibitive (in light of the average wages of direct service workers of \$10.85 per hour).
7. Many disability provider agencies have received little or no increase in reimbursement rates over the last 6 years, while health insurance rates have doubled in Wisconsin over that same period. This has resulted in a) an inability to provide wage increases, b) dramatic increases in employee cost-shares, c) many agencies eliminating the health insurance benefit, and d) some agencies on the verge of bankruptcy.
8. In some programs, e.g. Medicare Part D, people with disabilities and elderly people are presented with a bewildering set of choices, resulting in an over-dependence on expert advisors to navigate the choices, or passive acceptance of arbitrary auto-enrollment in a plan which is unlikely to meet the consumer's needs.
9. There is currently an unreasonable 2 year wait for Social Security Disability beneficiaries to get on Medicare.

Our Recommendations

Extrapolating from the problems listed above, we are asking you and the other members of the Wisconsin delegation to pursue the following objectives in your development of a final health care reform package:

1. Strengthen the Medicaid program and broaden eligibility for it, so more people with disabilities can use it and more providers will find the reimbursement rates acceptable.
2. Provide comprehensive coverage to ensure that health care is not discriminatory or irrelevant for people with disabilities. Specifically this includes: mental health and substance abuse treatment, chronic disease management, vision and dental care, rehabilitation services, occupational and physical therapy, home health care, in-home autism treatment, hearing aids, and cochlear implants (Note: in 2009 the Wisconsin legislature established statutory requirements for all Wisconsin health insurance companies to cover the cost of autism treatment, hearing aids, and cochlear implants.).
3. Ensure that the concept of "affordability" is applied realistically to people with disabilities, families and direct service workers who have very low incomes.

4. Ensure that employer costs are actually affordable to disability provider agencies (some of which meet the definition of "small business" and some do not), keeping in mind that these agencies have no control over their reimbursement rates from state government, county government, or managed care organizations. We are concerned that the "employer tax" included in some of the current proposals in Congress will not be affordable for many provider agencies.
5. Guarantee that no one can be denied coverage for any reason, including age, health status, occupation, family history, or preexisting conditions.
6. Eliminate the 2 year wait for Social Security Disability beneficiaries to get on Medicare.
7. Re choice of plans, ensure that a) the number of choices is not so large that it becomes bewildering for enrollees, b) the information on each plan is made available in a clear, transparent format, and c) all plans must meet basic requirements re quality and scope of service (so unsuspecting consumers are not subject to the danger of choosing or being auto-enrolled in a sub-standard plan).

Please feel free to contact any of us if you have questions about our concerns or recommendations.

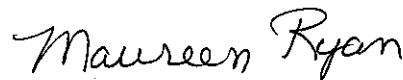
Sincerely,



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CC: Gov. Jim Doyle
 WI DHS Secretary Karen Timberlake

Encl.

2009 Membership List – Survival Coalition of Wisconsin Disability Organizations

- AARP- Wisconsin
- Arc Dane County
- Arc-Wisconsin Disability Association
- Autism Society of Southeastern WI
- Autism Society of Wisconsin
- Brain Injury Association of Wisconsin
- Community Alliance Providers of WI (CAPOW)
- Developmental Disabilities Coalition of Dane County
- Direct Care Alliance
- Disability Rights Wisconsin
- Employment Resources Inc.
- Epilepsy Foundation - South Central Wisconsin
- Family Voices
- Grassroots Empowerment Project
- Hearthstone
- Independence First
- Independent Living Council of Wisconsin, Inc.
- Independent Living Resources
- Mental Health America of Wisconsin
- Milwaukee Center for Independence
- NAMI Wisconsin, Inc.
- Options for Independent Living
- People First Wisconsin, Inc.
- Rehabilitation for Wisconsin, Inc.
- Service Employees International Union Local 150
- Society's Assets, Wisc
- The Steinhauer Group
- United Cerebral Palsy/ West Central WI
- Waisman Center
- Wisconsin Board for People with Developmental Disabilities
- Wisconsin Coalition for Independent Living Centers
- Wisconsin Council on Physical Disabilities
- Wisconsin Facets
- Wisconsin Occupational Therapy Association