
VOR Weekly E-Mail Update
July 31, 2009

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FEDERAL UPDATE

- 1. 60!** Additional cosponsors last week help H.R. 1255 reach new milestone - 60 cosponsors!. Have YOU requested a meeting or called your U.S. Representative?
2. Should Disability Funding Be Part of Health Reform? When it comes to their top legislative priority, disability activists fear later will mean never.
3. U.S. launches new disability website
4. Updated H.R. 1255 cosponsor list: Is your US Representative on the list. If not, August is your opportunity.

VOR and YOU

5. Shop online and benefit VOR with iGive.com

Coming Up: Massachusetts State Report - a lesson in effective grassroots advocacy.

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1. 60! Additional cosponsors last week help H.R. 1255 reach new milestone - 60 cosponsors!. Have YOU requested a meeting or called your U.S. Representative?

Wow! 60!

Thanks to new cosponsors Rep. Cathy McMorris Rodgers (R-WA) and Rep. Eric Massa (R-NY), who cosponsored H.R. 1255 this week, there are now 60 cosponsors!

See, <http://vor.net/AUGUSTINITIATIVE.htm>, for VOR's "If Not Us, Who"? August District Initiative Action Alert.

Nothing beats constituent contact, especially face-to-face if you are able to meet with your U.S. Representative in his/her District office. Of course, calls from constituents help too. Thank you for doing all you can do to help move H.R. 1255 through the Congressional process. Right now, numbers count. COSPONSORS count!

2. Should Disability Funding Be Part of Health Reform? When it comes to their top legislative priority, disability activists fear later will mean never

Summary: Article covers status of the Community Choice Act (aka MiCASSA), CLASS Act and Long Term Care in Health Care Reform discussions.

Ben Adler | July 30, 2009
The American Prospect

About the Author: Ben Adler is an urban leaders fellow at Next American City. His writing on urban and transportation policy has also appeared in The Atlantic and The Nation, among other publications.

With an estimated 37.5 million eligible voters with a disability -- and the aging baby boom generation means the ranks of the disabled will grow -- disability rights is an emerging brand of identity politics. The Democratic Party has been attuned to the change. The Democratic National Committee (DNC) disability caucus is growing in size and prominence. The Obama campaign had a comprehensive disability-issues platform, and President Obama hired Kareem Dale to be the first White House special assistant for disability policy. On July 21 the president also announced the U.S. will sign on to the United Nations Convention on the Rights of Persons with Disabilities.

So why are disability activists in an uproar? Instead of celebrating Obama's announcement, on July 21 a coalition of disability-rights organizations held 26 simultaneous protests at the DNC headquarters, local Democratic Party offices, and at Senate Finance Committee Chair Max Baucus' state office in Missoula, Montana. In April, 400 activists chained themselves to the White House fence and were arrested for civil disobedience. Why do they say they are being ignored, and even that they are victims of political discrimination? Because, like other key progressive constituencies, such as gay-rights and reproductive-rights advocates, disability-rights groups are watching long-awaited priorities be delayed as the president and Congress focus on the economy, climate-change legislation, and health reform.

The disability community's top legislative priority, the Community Choice Act (CCA), has been floating around Congress since 1997 and is distinct from any of the current health-reform bills under consideration. The CCA would make it mandatory, rather than optional, for states to offer Medicaid funding to people who would prefer long-term care at home instead of living in a nursing home. For disability activists, who regularly compare nursing homes to prisons, there is no issue more important. "We have 2 million disabled people stuck in institutions, the vast majority of whom don't want to be there," says Andy Imparato, president of the American Association of People with Disabilities. "They have been locked up without committing any crime."

When the bill was reintroduced in March, people with disabilities filled a small hearing room on Capitol Hill and spilled out into the hallway, raucously cheering the statements by Sen. Tom Harkin, the Iowa Democrat who is the original sponsor and a longtime champion of disability rights. Also present was Rep. Danny Davis (D-IL), who said he views disability rights as "a major civil-rights issue of our time." One wheelchair-bound man who had driven himself to Washington from Pennsylvania -- a state that already allows people with long-term care needs to access Medicaid funding for home services -- told me that under current law, if he lived in most other states, he would have to be in a nursing home.

The bill has not moved since its introduction. The White House and relevant Senate committees are consumed with health care, and neither Obama nor Democratic leaders in Congress have said

the CCA should be a part of the health-reform package, as disability-rights advocates believe it should.

As a senator, Obama was a co-sponsor of the CCA, and as a candidate, he promised to support it as president. John McCain opposed the bill, citing concerns about its cost. For many disability-rights activists this constituted the major distinction between the two candidates. They now feel they supported Obama under false pretenses. The administration contends that Obama's pledge to support the CCA never implied that it had to be a part of health-care reform and that the president still wants to enact it at a later date. Disability activists fear, however, that later will mean never. "The political capital used to pass health reform will make it very unlikely that Congress will want to tackle any health-reform cost expansion in the next couple sessions," says Jason Beloungy, a policy analyst at the National Council on Independent Living. "This is our one opportunity."

The White House and Senate Democrats have been extremely vague in their public statements on Community Choice, but activists identify four possible reasons for their reluctance to include it in health-care reform: political framing, cost, vested interests, and class. "It starts with the way the issue got framed during the election," Imperato says. "Obama's message was 'cover the uninsured, deal with costs of health care to keep companies competitive in the global market.' It's hard to fit the disability agenda of long-term service around those messages."

In terms of cost, it is cheaper to provide someone with a home health aide than to keep her in a nursing home, and so it is possible that the CCA would actually save money in the long run. However, many people -- no one knows precisely how many -- rely on the care of friends and relatives and maybe even make do with substandard care in order to stay in their home and out of an institution. In its initial years, it is likely the CCA would cause a short-term increase in cost as those people file to get home services. A Congressional Budget Office (CBO) estimate of an earlier version of the bill put the cost at around \$20 billion per year. While academic studies have made much lower estimates, in the vicinity of \$1.4 billion to \$3.7 billion per year, activists suspect Democrats fear adding to the nominal cost of the health-care-reform package. The CBO is currently rescoring the bill and is expected to estimate a cost of roughly \$5 billion annually.

Some activists contend that the businesses that would lose customers as a result of community choice -- what they refer to as "the nursing-home lobby" -- will not let the bill through without a fight. Had the CCA been included in health-care reform, these interests might have brought their lobbying muscle and campaign donations out against reform, further endangering the whole package's chances. But the nursing-home industry says it does not oppose the CCA. "We would see long-term care as part of health-care reform; it's very unfortunate that it's not," says Janice Zalen, senior director of special programs at the American Health Care Association, the largest federation of nursing-home, assisted-living, developmentally disabled, and sub-acute care providers.

"We like parts of [the CCA]. We have a couple concerns: It says it applies to all beneficiaries that need long-term care, but it's for people who are higher-functioning. It does nothing to help someone with severe mental retardation who needs 24-hour care. For the population that this bill really targets, it's excellent, but it needs to be made clear that this isn't the solution for everybody." Zalen contends that by making community choice mandatory, some states might

cover the additional cost by cutting funding for institutions, which some disabled people will still need.

Sen. Harkin's office supports Zalen's side of the story. "We have not heard from the nursing-home industry at all during this process," says Bergen Kenny, a spokesperson for Harkin. The misunderstanding may spring from the fact that in the past, the industry had more of an economic incentive to oppose community choice, before nursing-home companies started offering home health services themselves. Skeptics among the disability activists suggest that CCA opponents may simply be holding their fire and that individual institutions may be quietly lobbying their home-state representatives and senators.

Finally, there is the fact that the CCA is a bill that helps poor people, a group not known for their political leverage. A similar bill, the Community Living Assistance Services and Supports (CLASS) Act, which would create a national insurance program for people who become disabled as adults, was included in the Senate Health Education Labor and Pension Committee's version of health-care reform, as the White House proudly notes. The CLASS Act is specifically designed to prevent people from having to spend down their savings to qualify for Medicaid when they become disabled. Because one has to be a paid employee before becoming disabled to participate in the program, it is more of a middle-class benefit, while the CCA would also cover people who have severe disabilities from birth or childhood, a population that is disproportionately unemployed and impoverished. "Community Choice is seen as an issue addressing a poverty issue, not an institutional bias," says Bruce Darling, an organizer for CCA passage with ADAPT, the coalition of disability-rights activists who are focused on the Community Choice Act.

Advocates seem aware that the White House finds the urgency of their demand -- and their public activism -- befuddling and even irritating. On the morning of April 27, immediately prior to the protests outside the White House, White House health policy director Nancy Ann DeParle met with leaders from ADAPT. Participants report the meeting went poorly, with both sides essentially talking past each other. "I think she just missed the point," Darling says of DeParle. "I think some of their frustration is that they think they're nice people who are doing good things. She was saying, 'I understand your issues,' and we were saying, 'Not this one.'"

It turns out that one of Obama's strengths in appealing to disabled voters may be a liability when it comes to keeping them happy now that he is in office: the tendency of the disenfranchised to project their own values and aspirations onto his historic candidacy and lofty, if vague, rhetoric. "There were parallels drawn between Obama and Lincoln," Darling says. "A lot of people saw that through the prism of race. For us, it was a reference to freeing our people -- [Obama] would do what it took to free people who are locked up. [Now] you can just feel the anger over all of that."

Ultimately, the Obama administration faces an intractable conundrum: The very same administration that is being criticized in the media for trying to do too much all at once feels the weight of progressive issue groups that have been waiting since 1994 for a sympathetic president and Congress. Whether the Democrats will be left without political capital after health-care reform is unknowable. Disability activists don't want to take any chances finding out, but they are already growing resigned to the idea that they will have to wait, even as an aging population makes the problem grow larger. "I don't know when the next golden opportunity to address it will be," Imparato says. "We need to make it more of a presidential election issue in 2012."

3. U.S. launches new disability website

July 28th, 2009

Press release / Department of Labor

July 28, 2009

The federal government has launched a new website called Disability.gov, offering comprehensive information about programs and services geared to the more than 50 million Americans who have disabilities.

The new website aggregates information from 22 federal agencies and contains thousands of links. It was unveiled in conjunction with the 19th anniversary of the signing of the Americans with Disabilities Act.

Formerly known as Disabilityinfo.gov, the site includes mechanisms for encouraging interaction and feedback, and new ways to organize, share and receive information. It is organized into 10 subject areas: benefits, civil rights, community life, education, emergency preparedness, employment, health, housing, technology and transportation.

4. Updated H.R. 1255 cosponsor list: Is your US Representative on the list. If not, August is your opportunity.

H.R. 1255 Cosponsors

July 31, 2009

Total so far: 60!

Democrats (29)

Rep. James Moran (D-VA)*
Rep. Steve Cohen (D-TN)*
Rep. Paul Kanjorski (D-PA)*
Rep. Debbie Wasserman Schultz (D-FL)*
Rep. Michael Capuano (D-MA)
Rep. John Olver (D-MA)
Rep. John Barrow (D-GA)
Rep. Luis Gutierrez (D-IL)
Rep. John Larson (D-CT)
Rep. James McGovern (D-MA)
Rep. Pete Stark (D-CA)
Rep. Charles Gonzalez (D-TX)
Rep. John Lewis (D-GA)
Rep. Lynn Woolsey (D-CA)
Rep. Niki Tsongas (D-MA)
Rep. Sam Farr (D-CA)
Rep. John Sarbanes (D-MD)
Rep. Bobby Rush (D-IL)

Rep. Sheila Jackson-Lee (D-TX)
Rep. Mike Quigley (D-IL)
Rep. Richard Neal (D-MA)
Rep. Gwen Moore (D-WI)
Rep. Al Green (D-TX)
Rep. Lacy Clay (D-MO)
Rep. Russ Carnahan (D-MO)
Rep. Charles Melancon (D-LA)
Rep. Marion Berry (D-AR)
Rep. Bob Filner (D-CA)
Rep. Eric Massa (D-NY)

Republicans (31)

Rep. Ted Poe (R-TX)*
Rep. Ron Paul (R-TX)*
Rep. Bob Goodlatte (R-VA)*
Rep. David Dreier (R-CA)*
Rep. Dan Lungren (R-CA)*
Rep. Frank Wolf (R-VA)
Rep. John Culberson (R-TX)
Rep. Charles Boustany (R-LA)
Rep. Peter Roskam (R-IL)
Rep. John Boozman (R-AR)
Rep. Anh "Joseph" Cao (R-LA)
Rep. Pete Olson (R-TX)
Rep. Christopher Smith (R-NJ)
Rep. Judy Biggert (R-IL)
Rep. Brett Guthrie (R-KY)
Rep. Bill Cassidy (R-LA)
Rep. Gary Miller (R-CA)
Rep. Michael Burgess (R-TX)
Rep. Devin Nunes (R-CA)
Rep. Phil Gingrey (R-GA)
Rep. Sam Johnson (R-TX)
Rep. Steve King (IA)
Rep. John Fleming (R-LA)
Rep. Pete Sessions (R-TX)
Rep. Steve Scalise (R-LA)
Rep. Erik Paulsen (R-MN)
Rep. Kenny Marchant (R-TX)
Rep. Rodney Alexander (R-LA)
Rep. Randy Neugebauer (R-TX)
Rep. Michael McCaul (R-TX)
Rep. Cathy McMorris Rodgers (R-WA)

VOR and YOU

5. Shop online and benefit VOR with iGive.com

Going Shopping? Why not benefit VOR at the same time. Here's how:

- a. Visit, <http://www.igive.com>
- b. Select "Voice of the Retarded" as your cause (use the keyword search to find "Voice of the Retarded")
- c. Go shopping and a percentage of your purchase goes to VOR.

THANK YOU!

Editor: Tamie Hopp, VOR Director of Government Relations & Advocacy

THANK YOU FOR YOUR SUPPORT!

TO JOIN OR CONTRIBUTE: \$25 per individual, \$150 per family organization, or \$200 per provider/professional organization. Extra donations are welcome!

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