

VOR Action Item Reminders

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VOR Weekly E-Mail Update
September 11, 2009

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H.R. 1255 Cosponsors

Membership and Donation Form

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Federal Update:

1. H.R. 1255: 63 and counting! Time is now for follow up

Thanks to all of you who visited and called your U.S. Representative during August, when members of Congress were working from their District offices. The House reconvened this week. Since reconvening, 3 additional cosponsors have been added to H.R. 1255: Rep. Mike Ross (D-AR), Rep. Dean Heller (R-NV), and Rep. Donald Manzullo (R-IL). The complete cosponsor list is shared at the end of this Update. There are now 63 cosponsors. The list of supporters remains amazingly bipartisan: 30 Democrats and 33 Republicans. If you made contact with your U.S. Representative in August, now is a great time for follow-up. Members of Congress and their staff are dealing with many, many issues. It is up to YOU to keep H.R. 1255 on the radar screen and at the top of the pile. Follow up weekly - be friendly, but persistent.

THANK YOU!!

See, <http://vor.net/legislative-voice/legislation/hr1255>, for H.R. 1255 resources.

2. Dodd Said to Decline Kennedy Post

Update: Dodd did decline to Chair the Health, Labor, Education and Pensions (HELP) Committee, and Harkin did accept the Chair. The HELP Committee oversees issues of importance to VOR such as the DD Act Reauthorization.

By Paul Kane
Washington Post Staff Writer
Wednesday, September 9, 2009

Sen. Christopher J. Dodd (D-Conn.) has decided against succeeding his close friend and mentor, the late Edward M. Kennedy (D-Mass.) as chairman of the chamber's health committee, a senior Senate aide said Tuesday night.

The decision would set in motion a game of musical chairs involving committee chairmanships after Kennedy's death.

Sen. Tom Harkin (D-Iowa) is next in line after Dodd to assume the chairmanship of the Health, Education, Labor and Pensions Committee, and multiple sources in the Harkin orbit, speaking on the condition of anonymity because the deliberations are internal, said Harkin would be certain to take over the post.

Harkin is chairman of the Agriculture Committee, and he would have to give up that position to take over the health committee. He would probably be replaced by Sen. Blanche Lincoln (D-Ark.), who faces a difficult reelection bid in 2010. Three other Democrats on the committee have more seniority than her: Sens. Patrick J. Leahy (Vt.), Kent Conrad (N.D.) and Max Baucus (Mont.). But each holds a more prestigious chairmanship already: Judiciary, Budget and Finance, respectively.

Dodd has scheduled a news conference for 11 a.m. Wednesday to announce his decision. His aides did not respond to questions about the decision Tuesday evening, and the senator declined to answer reporters' questions as he entered the chamber for an evening vote.

While Kennedy battled brain cancer for 15 months, Dodd, Harkin and other Democrats on the committee divided up the chairman's responsibilities, with Dodd overseeing the panel's health-care legislation. When the Senate takes up that critical legislation later this year, Dodd is expected to continue being the public face of the committee's effort, a decision that might give him a boost in a tough reelection battle in 2010.

By remaining Banking chairman, Dodd would oversee the complex rewriting of regulations governing the financial services industry.

Reaching the Media: Choice Advocates Speak Out

3. Massachusetts: As I see it: Community, facility settings both serve a useful purpose

By Alfred V. Bacotti
Telegram & Gazette
January 30, 2009

About the author: Alfred V. Bacotti, Ph.D., is the retired facility director of the Glavin Regional Center.

As noted in a commentary in the Telegram & Gazette Jan. 16, the governor has decided to close state facilities for people with disabilities, including the Glavin Regional Center, within four years. The input and desires of the people living in these facilities and their families and guardians were not part of this decision-making process of coming to a conclusion or making a judgment.

Actually, the process of closing had begun prior to the announcement with the blocking of admissions and the failure to fill staff positions when they became vacant. In this decision, the role of facilities in taking care of the needs of individuals with mental retardation has been left out as well and, therefore, is largely unrecognized by the general public. Although the decision appears to already have been made, families of people who live at the facilities are still seeking to be heard on the issue.

The Jan. 16 article may have left a few misconceptions. Facilities are no longer an option for families with children who have developmental disabilities. Only adults over age 22 can be served at facilities and only when their needs greatly exceed the capacity of the community to support them.

In fact, getting admission into a facility is a difficult process and not taken lightly by anyone, even though each of the state facilities has a clinical expertise that has been developed over decades and is not generally available in the community at large. For example, the Monson Developmental Center provides state-of-the-art medical treatment for people with significant chronic health problems, while Templeton Developmental Center provides treatment for individuals with forensic problems and Glavin provides expertise for treating individuals with mental retardation and significant behavioral and mental-health issues.

Individuals who were admitted to these facilities over the past decade had been living in the community. Only after extensive efforts to meet their needs in the community had been attempted were they admitted to a facility. At times, the conditions warranting seeking assistance at facilities occurred only after multiple hospitalizations and multiple stays in psychiatric units at local hospitals.

Most people now living at Glavin came through the community system first. Facilities provide the treatment necessary to help these individuals return to their homes in the community. They are not seen as long-term residences. Facilities today, with their state of the art clinical services, are a backup to the community system.

There are also people living at the state facilities who came there years ago when our culture believed people with developmental disabilities could receive the necessary supports only outside their homes. This is not the case today. Our culture recognizes the importance of supporting people to live with their families in their communities. However, these people who have lived at facilities a long time, along with their families, see the facility they live at as their home. Closing the facilities, in their eyes, is not equivalent to obtaining a better quality of life.

A couple of arguments have been made to support the decision to close facilities. One is cost savings and the other is letting people become part of a community.

There is not likely to be any savings for the commonwealth from closing Glavin. Prior to coming into Glavin, it cost more to provide the necessary supports in a community.

It is also argued that closing Glavin would promote an improved quality of life because of the involvement in a community-based lifestyle. People living at Glavin are connected with their community. They go to work, attend church and volunteer at food banks.

At a recent informational meeting held on the closing of Glavin, a man told how his daughter had become friends with a man living at Glavin while playing on the soccer fields there and was concerned about where her friend at Glavin would live if they took away his home. How would they maintain their friendship?

People at Glavin are included in their community, not isolated from it, and the effect that general policy decisions have on individual lives has to be taken into account or the policy will contradict the intent.

The debate about community systems versus facility systems for people with disabilities is really a meaningless argument based on antiquated notions; both provide valuable services. Most people believe in community integration and in the right of families to be involved in making decisions that affect them

The debate should focus on families and individuals and how they want to be supported, not as a group with a label of disability, but as individuals, each with a unique set of needs.

4. Georgia's mental health care under review: New boss wants more workers, partnerships

Note: Ann Knighton, VOR Board Member, is quoted in the following article objecting to professionals showing daughter, Erica, who has profound mental retardation, pictures of community homes and asking Erica if she would like to live there. Ms. Knighton has filed an Office of Civil Rights Complaint alleging that families have been completely cut out of the process.

**By Tom Corwin | Staff Writer
Saturday, July 11, 2009**

The man who recently took over Georgia's troubled system for mental health and developmental disabilities knows he must start hiring more staff and reaching out to the state's universities for partnerships.

However, parents of patients at the Gracewood campus of East Central Regional Hospital want to ensure those vulnerable patients aren't dragged along in the push to move to community-based services.

Frank E. Shelp is the commissioner of the new Georgia Department of Behavioral Health and Developmental Disabilities, which was created July 1 during a reorganization of Georgia Department of Human Resources. He is making his way around to the state's mental health hospitals and community mental health centers and will be in Augusta next week. The department is also working on a needs assessment that Dr. Shelp hopes will be completed by September.

The state had been pursuing what had been dubbed the "Game Plan," which called for privatizing some mental health services, closing most regional hospitals and moving to community-based services for many patients. That worried parents including Theresa Senior, whose daughter, Terral, has been at Gracewood for 18 years and could not function on her own.

"It's not that we don't think people should be in group homes. We certainly do," Mrs. Senior said. "But those who can't function shouldn't be there."

Worse is how some of the Gracewood patients might be coerced into it, said Ann Knighton, whose daughter, Erica, has been at Gracewood since 1975 and suffers from severe deficits and seizure disorder.

Mrs. Knighton said during a conference Thursday that her daughter was shown pictures of houses by a social worker and asked whether she would like to live in the community.

The problem with that?

"She's never talked," Mrs. Knighton said. Asked how her daughter was supposed to answer the question, she said, "That's what I want to know."

The state is under a mandate to move patients to the less restrictive setting and to provide as much freedom for them as possible, but it should be the patient's wish, Dr. Shelp said.

"I would say I do understand the anxieties of the families involved, the vulnerability of their loved ones and maybe even their satisfaction with how things have gone up until now," he said. "We need to be sensitive and professional and still inquire as to other changes. Is there progress? Is there some hope that we need to be mindful of for something different? The answers for each individual may be different."

Part of the problem the state faces is staffing, Dr. Shelp acknowledged.

"I've inherited a hospital system that is significantly understaffed, in all areas," he said.

Part of it might be training.

"I think that we need to be concerned that we have a trained and skilled and professional staff that serve in these kinds of positions to help determine what people's true desires are," he said. "And I don't know that we have that right now. In fact, I'm pretty certain that we don't."

What might help is a greater affiliation between the state hospitals and the state's medical schools, including Medical College of Georgia. Dr. Shelp helped initiate a program in North Carolina between a state hospital and Duke University Medical Center that proved highly successful.

"Over a very short period of time, that state hospital became the most favored rotation site of both residents and medical students," he said. "It's a situation where everyone benefits."

5. Colorado: Penry rips plan to close Grand Junction nursing unit

By Tim Hoover
The Denver Post
September 9, 2009

State Senate Minority Leader Josh Penry and other Republicans have repeatedly said that Democratic Gov. Bill Ritter isn't making the "tough choices" to cut spending in order to balance the budget.

But when Ritter last month announced one particular cut, the closure of a 32-bed nursing unit for developmentally disabled patients in Penry's hometown of Grand Junction, Penry and other Western Slope Republicans pounced.

Penry, who is running for governor, called the closure, which would save \$1.3 million, ill conceived, saying Ritter's administration had no plan to place the physically fragile patients in community settings.

"Many, if not most, of the people in that wing need a high level of care," said Penry, who was quoted as calling the decision to close the unit "classic back-of-the-napkin budgeting from this governor" in an Aug. 22 story in the Grand Junction Sentinel.

Evan Dreyer, a spokesman for Ritter, said there is a plan to place the patients in community care, adding that Penry's criticism of the closure of the unit in his own district smacks of hypocrisy.

"Closing a \$1.8 billion budget shortfall because of the recession required difficult choices and painful decisions," Dreyer said. "This is one of them."

"Complex" needs

First created in 1921 as the State Home for Mental Defectives, the regional center in Grand Junction cares for 145 patients, primarily ones with developmental disabilities who do not require constant nursing care. Those in the 32-bed unit, though, are severely developmentally disabled and have physical disabilities, said Sharon Jacksi, director of the state's Division for Developmental Disabilities.

"They're individuals that have really complex medical needs," said Jacksi, a former director of the Grand Junction Regional Center. "Some were born, for example, with very severe cerebral palsy and mental retardation. The vast majority of the 32 are wheelchair-bound. They need total care."

Jaksi said the division believes they would be better served in group or nursing homes, adding that the division provides services for at least 260 patients with similar needs in group homes across the state. She said the trend in recent decades has been to get such patients out of state-run institutions and into community placements such as group homes, where they are in smaller settings and also can more easily integrate with society at large.

The budget cuts Ritter announced last month, which would cut about \$260 million in general-fund spending, spread pain across programs statewide. For example, the plan also includes eliminating 59 beds for the mentally ill at a Fort Logan facility, cuts in payments to rural health clinics, elimination of a subsidy for senior dental care, and cuts to anti-youth-violence and early-education programs.

But few cuts have received greater attention than the closure of the unit at the Grand Junction Regional Center.

Penry over the past year has lambasted Ritter and Democrats, who control the legislature, as being unwilling to cut programs.

"During difficult times like these, leadership is about confronting reality and making the tough choices today that are necessary for a better tomorrow,"

Penry wrote in a guest column for The Denver Post in May.

Penry stresses that he never suggested that the unit shouldn't be closed, only that it was wrong to close it without a plan for placing all the patients in appropriate care. He said the planned closure likely would be tied up in a lawsuit.

Courts "won't have it"

"Some reorganization (of the unit) is probably in order," Penry said, "but the wholesale closure of it without a plan just ain't happening because the courts just won't have it."

Jacksi said the division will work with individual patients and their families or guardians to ensure each one receives appropriate placements. Only after all patients have been placed in community care will the unit be closed, she said.

Connie Robbins-Brady, a Grand Junction woman whose 25-year-old son is a patient at the unit, said a letter she received from Penry left her with the impression that, like her, he opposed the unit's closure.

"Let me assure you that I too am deeply troubled by the ill-conceived plan to displace patients without a reliable alternative option that will meet the needs of both the patients and their families," Penry wrote.

Robbins-Brady said she assumed "that he supported what we were doing" to keep the unit open and opposed the closure.

Having it both ways?

Rep. Mark Ferrandino, D-Denver, a member of the legislature's Joint Budget Committee, said Penry was trying to have it both ways, appearing sympathetic to local advocates who oppose the closure while looking tough to fiscal conservatives by not technically opposing the closure.

"I'm really glad Sen. Penry realizes the importance of services," Ferrandino said. "It's just striking that he only realizes that when it happens in his own neighborhood."

Republican Reps. Steve King of Grand Junction and Laura Bradford of Collbran, who oppose outright the unit's closure, also have called for greater fiscal restraint from Democrats. Both, though, said closing the unit in their district was the wrong way to go about it.

"It's not that I don't want to make an effort in shrinking government," King said.

"I just think this is the wrong hard decision."

Bradford said she was working with King on a plan to find alternative savings in the regional center budget while still not closing the 32-bed unit. She said closing the unit would be "a death warrant" for the patients in it.

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H.R. 1255 Cosponsors

September 11, 2009

Total: 63

Sponsor: Rep. Barney Frank (D-MA)

Democrats (30)

- Rep. James Moran (D-VA)*
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- Rep. Paul Kanjorski (D-MI)*
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- Rep. Bob Filner (D-CA)
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- Rep. Bob Goodlatte (R-VA)*
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* Original Cosponsors

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

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