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Distribute Annual Meeting/Initiative Flyers and Sponsorship Flyers
Put information about these opportunities in your newsletters.
Sponsor someone from your group to attend the meeting.
Contact Tamie at 605-399-1624; Tamie327@hotmail.com for information

VOR Weekly E-Mail Update

April 24, 2009

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1. BULLETIN BOARD: "If Not Us, Who" Action Reminders

SUPPORT H.R. 1255:

This legislation will only pass with VOR grassroots advocacy efforts. See VOR's website for more details.

CHOICE PETITION NOW TOPS 1,500 SIGNATURES!

Keep up the great effort! Efforts by VOR's grassroots have shifted from signing the Petition to getting others to sign it! One advocate in Wisconsin has enlisted at least 30 people, from her hairdresser to her banker, who respond "Support choice? Why not?" To add your name, visit <http://www.vor.net> and link to the petition via the VOR homepage.

VOR Annual Meeting and Washington Initiative Deadlines:

Hotel Registration: May 12, 2009
Annual Meeting Registration: May 31, 2009 (for early bird prices)
See, <http://www.vor.net/AnnualMeeting2009.htm>, for details

2. VOR Responds to DD Act Programs Request for Significant Increase in Funding

Action! The following Position Paper was faxed to the 90 members of the U.S. Senate and House Appropriations Committees. You are encouraged to contact your Representative and Senators, especially if they serve on the Senate or House Appropriations Committees, and ask that they OPPOSE any increased funding for DD Act programs, especially because these programs have operated with virtually no Congressional oversight for nearly a decade. To see if your Representative or Senators serve on House or Senate Appropriations Committees, visit, <http://appropriations.house.gov/> and <http://appropriations.senate.gov/>.

VOR POSITION PAPER (April 2009)

Sidebar: About VOR:

VOR is a national organization advocating for the right of individuals with developmental disabilities and their families to choose from a full array of high quality residential and other support options.

VOR members feel strongly, based on their individual experiences, that services received, regardless of setting, should be based on individual need and choice, whether in a family home, own home, community setting, or a facility.

Please Exercise Caution!

Level Fund DD Act Programs for FY 2010

Reject Requests for Increased FY 2010 Appropriations for DD Act Programs

The three primary grant programs authorized by the Developmental Disabilities Assistance and Bill of Rights Act (DD Act) - state Developmental Disabilities Councils (DD Councils), state Protection and Advocacy (P&A) systems, and state University Centers for Excellence in Developmental Disabilities (UCEDD) - have collaborated to request an unprecedented annual increase for themselves of more than 13% (\$20 million) in FY 2010 appropriations.

This request comes despite the fact that there have been NO Congressional oversight hearings of these programs since 2000. Moreover, despite legitimate questions regarding program outcomes, appropriations for these programs have already been increased by 33% since 2000 .

It has been nearly a decade since the DD Act of 2000 has been reauthorized, and it is not anticipated that a reauthorization bill will be considered until late 2009, if at all this year.

Since the last reauthorization, the membership of the House and Senate authorizing committees has changed by 79% in the House and 72% in the Senate. ExpectMore.gov, developed by the White House Office of Management and Budget in collaboration with federal agencies, ranks the DD Act grant programs as only "adequate," noting that "While the program has performance measures, it lacks an efficiency measure to assess its cost-effectiveness and independent evaluations to assess its impact."(<http://www.whitehouse.gov/omb/expectmore/summary/10001056.2003.html>).

Likewise, VOR seriously questions whether the DD programs are achieving their goals and submits that some federally-financed activities by these programs to eliminate Medicaid-licensed and funded Intermediate Care Facilities for Persons with Mental Retardation (ICFs/MR) are harming ICFs/MR residents and others who desperately need this specialized service option: our most needy citizens with severe and profound mental retardation and related developmental disabilities. In its report, "Abuse of DD Act Programs' Powers & Resources," the VOR DD Act Task Force documents more than 70 examples from 20 states of DD Act programs' anti-facility bias, the downsizing and closures that have resulted, and the sometimes tragic outcomes. See, <http://www.vor.net/DDActAbuseUS.htm> for a summary of this report.

The choice of an ICF/MR is one of a range of service options specifically supported by Medicaid law, the DD Act and the Supreme Court. Congressional scrutiny is desperately needed. Until Congress is able to carefully examine the DD Act federal grant programs and make badly needed

changes, VOR calls on Congress to exercise fiscal caution: reject proposals for increased appropriations and level fund the DD Act programs in FY 2010.

ATTACHMENT

Federal law does NOT mandate the closure of ICFs/MR and requires the involvement of families in making decisions

Federal law created the ICF/MR program

ICFs/MR are Medicaid-certified and funded. For a program to be licensed as an ICF/MR, the Centers for Medicare and Medicaid Services (CMS) within HHS must certify, annually, that it meets 8 conditions of participation including, but not limited to, client protection, adequate staffing, and appropriate health care. Within the eight conditions there are 378 specific federal standards and elements which every licensed ICFs/MR must meet to remain federally-certified and funded. Through Medicaid, CMS also administers the Home and Community-Based waiver program as an alternative to ICFs/MR.

The DD Act does not mandate deinstitutionalization

"Furthermore, the Committee would caution that goals expressed in this Act to promote the greatest possible integration and independence for some individuals with developmental disabilities not be read as a Federal policy supporting the closure of residential institutions. It would be contrary to Federal intent to use the language or resources of this Act to support such actions, whether in the judicial or legislative system." [House Energy and Commerce Committee Report No. 103-378, November 18, 1993, pages 7-8 (to accompany H.R. 3505, the Developmental Disabilities Assistance and Bill of Rights Act Amendments of 1993, Section-by-Section Analysis, Section 3, adding Purposes and Policies to Findings)].

The DD Act recognizes individuals and their families as the "primary decisionmakers"

"Individuals with developmental disabilities and their families are the primary decisionmakers regarding the services and supports such individuals and their families receive, including regarding choosing where the individuals live from available options, and play decisionmaking roles in policies and programs that affect the lives of such individuals and their families." (42 U.S.C. §15001(c)(3)(2000)).

The DD Act states it is the right of individuals with developmental disabilities to receive publicly supported treatment, services and habilitation that are appropriate to needs of the individuals

"The Federal Government and the States both have an obligation to ensure that public funds are provided only to institutional programs, residential programs, and other community programs, including educational programs in which individuals with developmental disabilities participate, that . . . provide treatment, services, and habilitation that are appropriate to the needs of such individuals . . ." (42 U.S.C. §15009(a)(3)(A)(2000)).

The Supreme Court (Olmstead) supports a full array of residential options and requires choice

In *Olmstead v. L.C.*, the U.S. Supreme Court very clearly supports choice in residential options, finding that the decision of where someone is served must be grounded on need, choice and available resources (119 S. Ct. 2185, 2181 (1999), see also at 2187, "We emphasize that nothing in the ADA [Americans with Disabilities Act] or its implementing regulations condones termination of institutional settings for persons unable to handle or benefit from community settings . . . Nor is there any federal requirement that community-based treatment be imposed on patients who do not desire it").

3. KENTUCKY: Federal Funding Restored to Three Oakwood Units

Statewide News Release
March 23, 2009

FRANKFORT, Ky. - Gov. Steve Beshear today announced the Centers for Medicare and Medicaid Services (CMS) has verbally informed the state that federal funding has been restored to three of Oakwood's four units.

CMS recertified Units #2, #3 and #4 after accepting plans of correction related to deficiencies identified during a follow-up survey on Jan. 9. Funding was restored to Unit #2 retroactive to March 13; Unit #3 retroactive to Feb. 5; and retroactive to March 4 for Unit #4.

The Cabinet for Health and Family Services (CHFS) is awaiting official word from CMS.

"This is a tremendously significant accomplishment in our efforts to restore federal funding for the entire facility," said Gov. Beshear. "Although a few hurdles remain, I am extremely proud that Oakwood has demonstrated such dramatic progress, and three of the four facilities have now been reinstated to the Medicaid program."

"Restoring certification is an uphill battle for any facility, but we have never lost sight of our goal of addressing the significant issues Oakwood faced at the beginning of this long road," said CHFS Secretary Janie Miller. "We're pleased to be in the position of achieving recertification for three of the four units, and are optimistic that the other unit is close behind."

"The Cabinet has worked hard to place Oakwood on a clear path to recertification, and I commend all the staff for their dedication and commitment. I would particularly like to thank Acting Deputy Commissioner Betsy Dunnigan (Department for Mental Health, Developmental Disabilities and Addiction Services) for her tireless efforts on behalf of the facility."

Unit #1 did not pass the initial survey, which occurred last September. CHFS has been working with the Bluegrass Regional Mental Health-Mental Retardation Board, which manages Oakwood, to address the deficiencies cited in Unit #1. CHFS plans to resubmit an application to CMS for the unit in the next few weeks.

The state has funded Oakwood since federal funding ceased in May 2008. Oakwood's annual budget is approximately \$75 million, \$60 million of which was originally anticipated to be Medicaid funds (federal and state).

ecertification of Unit #2 means the restoration of around \$980,000 monthly in federal funds paid to the state; approximately \$700,000 per month for Unit #3; and in approximately \$840,000 monthly for Unit #4.

Oakwood, the state's largest facility for adults with mental retardation, is located in Somerset. Its current census is 201.

4. IOWA: DHS rejects proposal to shutter Glenwood

Summary. Responding to Iowa Protection and Advocacy's call for Glenwood to be closed, Department of Human Services Director Gene Gessow and several of his administrators issued a written statement in which they said residents' needs are being met at the home and the department remains committed to "excellence and dignity." Sybil Finken, VOR's First Vice President, has a son, Seth, 29, who has lived at Glenwood for 25 years. She calls herself "Glenwood's No. 1 cheerleader," and argues that Iowa's efforts to expand community-based services are needed, but shouldn't come at the expense of places like Glenwood. "We need the full spectrum of choices," she said. "In other states, they've closed institutions and the people who were living there were left with no place to go."

IOWA: DHS rejects proposal to shutter Glenwood

By CLARK KAUFFMAN

April 24, 2009

(Excerpts)

Top administrators at the Iowa Department of Human Services said Thursday they are committed to providing "state-of-the-art care" for the disabled residents of the Glenwood Resource Center.

The administrators were responding to an advocacy group's call for Glenwood to be closed because of recurring problems with resident care.

"Glenwood's model of care is antiquated - it cannot be repaired or fixed," said Iowa Protection and Advocacy in a report issued Thursday. "Despite runaway expenditures, Glenwood residents have died in the last 14 months at an alarming rate."

A spokesman for Gov. Chet Culver said the governor will review the report and discuss it with others.

Responding to Iowa Protection and Advocacy's call for Glenwood to be closed, Department of Human Services Director Gene Gessow and several of his administrators issued a written statement in which they said residents' needs are being met at the home and the department remains committed to "excellence and dignity."

In addition, two parents who have sons at Glenwood defended the home Thursday in interviews with *The Des Moines Register*.

Glenwood, which is home to more than 300 mentally and physically disabled children and adults, has been under federal scrutiny for 10 years. Since 2004, it has been unable to meet court-ordered standards of care outlined in an agreement with the U.S. Department of Justice.

Iowa Protection and Advocacy, which is part of a network of privately run organizations created by Congress to help protect the rights of the disabled, wants the state to close Glenwood over the next 30 months and address residents' needs through community-based services.

The Department of Human Services says it has been expanding those types of services so fewer disabled Iowans will have to be institutionalized at Glenwood or its sister facility, Woodward Resource Center.

However, the department also says residents now living at the two facilities have "enormous needs" and currently there are no other options available for their care.

Richard Crouch, who heads a support group for the families of Glenwood residents, said Iowa Protection and Advocacy seems to be engaged in "a last-ditch effort to just stir up more trouble." His son, Gary, 38, has lived at Glenwood for 22 years.

He said some of Glenwood's residents need the sort of intensive, 24-hour care that probably can't be provided through community-based services. Before the state even considers closing Glenwood, it should have proven alternatives in place, he said.

Sybil Finken has a son, Seth, 29, who has lived at Glenwood for 25 years. She calls herself "Glenwood's No. 1 cheerleader," and argues that Iowa's efforts to expand community-based services are needed, but shouldn't come at the expense of places like Glenwood.

"We need the full spectrum of choices," she said. "In other states, they've closed institutions and the people who were living there were left with no place to go."

Sylvia Piper, executive director of Iowa Protection and Advocacy, said others states have made a successful transition from institutional care to community-based care, and Iowa can, too.

She said that over the past few decades, 155 institutions around the country have closed, and nine states now have no such facilities. She said community care is typically cheaper to provide than institutional care and provides a more home-like environment. Piper said the recommendation for closure is not a call for another study of Glenwood, but rather a demand for change. She said the issues at Glenwood have been "studied to death" over the years.

"We're saying, 'No more.' If it requires litigation, we're going to go that route - but we hope that isn't going to be the case," she said.

More than half of the Glenwood residents are profoundly retarded and three-fourths of them have a life-threatening swallowing disorder. A third are completely dependent on others to move about, and many cannot speak, which makes diagnosis and treatment difficult.

Additional Facts **DHS statement regarding Glenwood Resource Center**

Iowa Department of Human Services Director Gene Gessow, Deputy Director Sally Titus, Acting Glenwood Resource Center Superintendent Kelly Brodie, Woodward Resource Center Superintendent Jim Finch and Bill Gardam, Acting Administrator of the DHS Division of Mental Health and Disability Services, issued this statement Thursday in response to a recommendation from Iowa Protection and Advocacy that the department close the Glenwood Resource Center for disabled children and adults:

The Iowa Department of Human Services is committed to state-of-the-art care for people with disabilities in all settings. At Glenwood and Woodward, we have been tested - rightfully so - by difficult and demanding standards of the Department of Justice over the last several years. Just two weeks ago Woodward was found to be in full and robust compliance.

We mention Woodward's achievement because we know that Glenwood is not far behind.

Our commitment to excellence and dignity on these two campuses is not just on paper. Iowans can see it for themselves. **We invite anyone to visit Glenwood, as many legislators have done this year.**

Perhaps our toughest test comes from relatives who frequently visit their loved ones and who insist on the best care. The relatives have formed a support group and we invite anyone to ask them about how we're doing.

Like Iowa Protection and Advocacy, we are committed to serving people with disabilities in home or community settings when it can be done with safety and dignity. Two years ago we secured an enormous federal grant - the \$50 million "Money Follows the Person" grant - to help develop community options. Over the past five years DHS has expanded community-based services for people with disabilities through the Medicaid-waiver program.

As a result, dozens of former Glenwood and Woodward residents are now living in security and dignity in home-like settings. While both WRC and GRC admit new residents who need our services, the overall populations at both Woodward and Glenwood are in steady decline.

The people who remain on our campuses have enormous needs. Alternative options have typically been exhausted. At Glenwood, more than half of the residents are profoundly retarded, three-fourths have a severe life-threatening swallowing disorder, half have a seizure disorder, two-thirds have a diagnosed mental illness, a third are completely non-ambulatory, and many cannot speak and thus have difficulty participating in their care.

We are meeting needs of these people at Glenwood and Woodward. We also are transparent. We post all of the Department of Justice documents that track our progress on our Web site. The address is: <http://www.dhs.state.ia.us/Consumers/Facilities/DOJ/DOJ.html>.

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**VOR MEMBERSHIP/CONTRIBUTION FORM
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!

You may pay by check or credit card

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