

January 2009

## VOR Policy Recommendations for Consideration By President-Elect Barack Obama

### A. ABOUT VOR

The disability community is quite diverse, ranging from people with some physical limitations to people whose cognitive and/or physical limitations are so significant that they function at the level of a newborn or an infant.

While many Americans are familiar with the people with disabilities who are able to work at local businesses, few have any appreciation of the people with severe disabilities who require around the clock care.

Given the diversity of persons in the developmental disabilities community, VOR strongly supports a continuum of quality care options to meet the wide range of needs, ranging from family home, own home, other community-based options, to Medicaid-licensed facility-based care (ICFs/MR).

We **support** the expansion of quality community-based service options; we **oppose** the elimination of the ICFs/MR (institutional) option.

VOR's support for the right of individuals and their families to choose from an array of residential options, based upon individual need, including, but not limited to, ICFs/MR, sets our organization apart from all other national advocacy organizations who feel the ICF/MR option is not necessary. We are the **only** organization that advocates for a full range of choices rather than defining "choice" artificially narrowly to meet an ideological agenda.

VOR's membership is comprised primarily of families of individuals with profound developmental disabilities whose lives depend on high quality, specialized, compassionate supports. We are not providers of care; our only motive is the well-being of our loved ones. There is federal support for our perspective:

Olmstead v. L.C., 119 S. Ct. 2176, 2187(1999): "We emphasize that nothing in the ADA 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."

Developmental Disabilities Assistance and Bill of Rights Act, 42 U.S.C. 15001(c)(3)(2000): "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."

Rep. Barney Frank (D-MA): In an effort to correct a national injustice, Rep. Frank introduced legislation to ensure that ICF/MR residents and, where appointed, their legal guardians, are notified of pending class action lawsuits and are given an opportunity to opt out of such lawsuits if they wish to remain in the ICF/MR (see the discussion below relating to "Class Action Reform").



## B. POLICY POSITIONS

### 1. MEDICAID AND LONG TERM CARE

For many people with mental retardation, Medicaid programs provide the most basic life-sustaining services, from the health care they receive to the places they call home.

VOR urges the Obama Administration to ensure that Medicaid beneficiaries are protected as health care and budget reforms are pursued. Specifically, VOR cautions the Administration not to unintentionally neglect the needs of ICF/MR residents in its “support for independent, community-based living to ensure individuals with significant disabilities have a choice to live in the community.” VOR shares the view that people should have the “choice” to live in the community but that opportunity must not come by eliminating the ICF/MR option for those who choose it. Ideology should not trump true choice.

Specifically, VOR urges President-Elect Barack Obama and his administration to --

- a. **SUPPORT** continuation of the Medicaid Intermediate Care Facilities for Persons with Mental Retardation (ICFs/MR) program; **OPPOSE** proposals to weaken or eliminate the ICFs/MR program.
  - i. **ICFs/MR are not Nursing Homes:**

Nursing homes are a mandatory Medicaid benefit, *i.e.*, an entitlement for those eligible. ICFs/MR are an **optional** Medicaid benefit, provided only if a state chooses to do so (although they are absolute necessity for the survival of the people they serve). Nursing homes and ICFs/MR serve entirely different populations. See Attachment A, “Medicaid: Optional v. Mandatory Services under the Law.”
  - ii. **ICFs/MR are a part of the community in which they are located:**

ICF/MR residents visit local restaurants and participate in community events. Many facilities share their campuses with other community groups, public schools, summer camps, and/or day care centers. ICFs/MR are not isolated but well integrated into their “community” – sometimes more so than “community-based” individuals who, due to lack of staff or transportation, find themselves isolated.
  - iii. **ICFs/MR are the “intensive care unit” of the disability service system:**

ICFs/MR provide compassionate support to medically fragile and behaviorally complex people with profound developmental disabilities, many of whom have the cognitive ability of infants. For these residents, ICFs/MR are often the most appropriate and humane specialized life-sustaining placement option.
  - iv. **There is no “institutional bias” for DD people / services:**

Most (2/3) of Medicaid long term care spending on developmental disabilities programs is for community-based programs. Only 1/3 of Medicaid long term care spending for people with developmental disabilities is directed at institutional programs (ICFs/MR).
  - v. **ICFs/MR deliver cost effective, quality care:**

ICF/MR care costs are comparable to community care costs when one examines the same population of people and the same constellation of services. Support for the ICF/MR option by the families of ICF/MR residents attests to the quality of care most ICF/MR residents receive. Nationally, ideologically-driven deinstitutionalization has led to resident regression, abuse, neglect and even death.



- b. **OPPOSE** proposals to make all Medicaid community-based services mandatory Medicaid programs, **unless** other optional Medicaid programs, such as ICFs/MR, are also made mandatory.
  - i. In December 2008, the Congressional Budget Office has estimated that proposals to make all community-based Medicaid programs mandatory, including but not limited to personal attendant care, would increase Medicaid spending by about \$10 billion per year.
  - ii. These new Medicaid costs would place a significant mandatory burden on states already facing budget and program cuts. Absent making the ICF/MR option also mandatory, the additional burden of making all community-based services mandatory would necessitate further cuts to optional Medicaid programs, such as ICFs/MR.

## 2. **DISABILITY CLASS ACTION REFORM**

In 19 states, HHS-funded Protection and Advocacy (P&A) agencies have filed 28 federally-funded class action lawsuits involving Medicaid licensed and HHS funded ICFs/MR. This absurd scenario – HHS v. HHS – is ideologically motivated. Since 1996, none of these lawsuits involved conditions of care; all sought ICFs/MR downsizing or closure. Fifteen of these cases have led to the closure of ICFs/MR, affecting thousands of individuals with mental retardation, often with disastrous results (see *e.g.*, California and Washington, D.C.).

Current law does not require that attorneys notify the prospective class members (residents) or their guardians that a lawsuit is about to be filed against the care facility where their loved one resides. Cases can proceed without their knowledge or, if residents and their legal guardians become aware of the lawsuit, over their express objections.

VOR urges President-Elect Obama and his administration to --

- a. **SUPPORT** class action reform consistent with H.R. 3995, sponsored by Rep. Barney Frank in the 110<sup>th</sup> Congress and supported by 42 cosponsors from across the political spectrum. H.R. 3995 proposed --
  - i. Requiring that prospective class members (residents of ICFs/MR) and their legal guardians receive notice of a federally-funded class action lawsuit involving an ICF/MR before the lawsuit is filed; AND
  - ii. Providing prospective class members and their legal guardians a time-limited opportunity to opt out before the lawsuit is filed.

## 3. **DEVELOPMENTAL DISABILITIES ASSISTANCE AND BILL OF RIGHTS ACT (DD Act)**

The DD Act's reauthorization is anticipated in 2009, nine years after the last reauthorization.

Many DD Act programs and activities have sought to eliminate the ICF/MR option. Through lawsuits, lobbying, media and advocacy they disregard individual and family/guardian choice and ignore the needs of the affected individuals. In doing so, they act in clear violation of DD Act and related Congressional intent:



“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.” DD Act, 42 U.S.C. 15001(c)(3)(2000) (*Findings, Purposes and Policies*).

“[T]he 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 Report No. 103-378, Nov. 18, 1993, pages 7-8 (to accompany H.R. 3505, Developmental Disabilities Assistance and Bill of Rights Act Amendments of 1993, Section-by-Section Analysis, Section 3, adding Purposes and Policies to Findings)).

See also, *Olmstead v. L.C.*, 119 S. Ct. 2176 (1999) in which the Justices held that one condition for community care is that “The transfer from institutional care to a less restrictive setting is not opposed by the affected individual” (at 2181) and stated “We emphasize that nothing in the ADA 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.” (at 2187).

To help ensure that the federally-funded DD Act programs operate within their mandate to the benefit, and not harm, of individuals with severe and profound mental retardation and developmental disabilities, VOR strongly urges President-Elect Obama and his administration to --

- a. **SUPPORT** amendments to the DD Act aimed at ensuring that DD Act program recipients carry out the Act’s express mandate to respect choice in residential settings and family decisionmaking.
- b. **SUPPORT** an HHS audit of how DD Act programs are working and whether they are respecting family choice and the *Olmstead* Supreme Court decision.

#### 4. **FUNDING FOR SOCIAL SECURITY and MEDICAID**

VOR urges President-Elect Obama and his administration to --

- a. **SUPPORT** a temporary increase in FMAP, the Federal Medicaid Assistance Percentage for Medicaid. Given the budget crises gripping most states, Medicaid is being cut despite increasing needs.
- b. **SUPPORT** funding for the Social Security Administration to address the serious hearings backlog. Currently there are over 760,000 hearings pending. Many claimants’ conditions worsen and some even die while waiting 500 days for a hearing.

#### 5. **STAKEHOLDER INVOLVEMENT**

VOR urges President-Elect Obama and his administration to --

**SUPPORT** continued inclusion of all disability advocacy perspectives in policymaking discussions and collaboration among disability groups for the betterment of all Americans with developmental disabilities.



Thank you for your thoughtful consideration. We appreciate the opportunity to share our insights and positions on behalf of our constituency with mental retardation and developmental disabilities. We look forward to working collaboratively with the Obama Administration to represent our constituency in policymaking forums.

### **For More Information**

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**ATTACHMENT A**

**Medicaid: Optional v. Mandatory Services Under the Law**

<b><u>Mandatory - Acute</u></b>	<b><u>Optional - Long Term Care</u></b>
<ul style="list-style-type: none"> <li>*Physician, nurse practitioner and nurse midwife</li> <li>*Laboratory and x-ray</li> <li>*Inpatient and outpatient hospital services</li> <li>*EPSDT (early intervention)</li> <li>*Family planning</li> <li>*Federally-qualified health center and rural health clinic</li> </ul>	<ul style="list-style-type: none"> <li>*Intermediate care facility for persons with mental retardation (ICFs/MR)</li> <li>*Home and community-based waiver services</li> <li>*Inpatient and nursing facility services for people 65 or over in an institution for mental diseases</li> <li>*Inpatient psychiatric hospital services for children</li> <li>*Home health care</li> <li>*Case management</li> <li>*Respiratory care services for ventilator-dependent individuals</li> <li>*Personal care services</li> <li>*Private duty nursing services</li> <li>*Hospice care</li> <li>*PACE services (Programs of All-inclusive Care for the Elderly )</li> </ul>
<p style="text-align: center;"><b><u>Mandatory - Long Term Care</u></b></p>	
<ul style="list-style-type: none"> <li>*Nursing facility services for adults</li> <li>*Home health care services (for people entitled to nursing facility care)</li> </ul>	
<p style="text-align: center;"><b><u>Optional - Acute</u></b></p>	
<ul style="list-style-type: none"> <li>*Medical care or remedial care furnished by licensed practitioners under state law</li> <li>*Diagnostic, screening, preventative, and rehabilitative services</li> <li>*Clinic services</li> <li>*Dental services</li> <li>*Physical therapy and related services</li> <li>*Prosthetic devices</li> <li>*Eyeglasses</li> <li>*TB-related services</li> <li>*Primary care case management</li> <li>*Other specified medical and remedial care</li> </ul>	

**Medicaid Beneficiary Groups**

<b><u>Mandatory</u></b>	<b><u>Optional</u></b>
<ul style="list-style-type: none"> <li>*Low-income Children</li> <li>*Children in foster care</li> <li>*Parents with income below state-established minimums</li> <li>*Elderly and disabled SSI beneficiaries</li> <li>*Low-income Medicare beneficiaries</li> </ul>	<ul style="list-style-type: none"> <li>*Children and parents above minimum income requirements</li> <li>*Low-income pregnant women</li> <li>*Low-income disabled and elderly people, incl. Nursing home residents</li> <li>*Disabled and elderly people served under Home and Community Based waivers</li> <li>*Women with breast and cervical cancer</li> <li>*Certain disabled people who are employed and buy into coverage</li> </ul>