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**June 4 - 9, 2010**

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**VOR Weekly E-Mail Update**  
**November 13, 2009**  
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**1. ICFs/MR as Permanent Homes: Illinois families join others in making their case to the Governor**  
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**Website update:** This letter can also be found on VOR's Website, in the [Toolkit for Families](#) and [Legal Resource](#) sections.

**Summary:** The following letter, signed by 30 organizations, sets forth the legal rationale for "ICFs/MR as Permanent Homes." The letter was written by Rita Burke, VOR Illinois State co-Coordinator and President of the Illinois League of Advocates for the Developmentally Disabled (IL-ADD). It was presented to Illinois Governor Patrick Quinn earlier this week. Although motivated by a situation in Illinois, the letter, which includes federal citations to support the right of ICFs/MR based on individual eligibility and choice, is applicable across the country. The body

of the letter could be adapted to any state and collecting the support of many organizations from your state is a great advocacy tool as well.

November 12, 2009

The Honorable Patrick Quinn  
207 Statehouse  
Springfield, Illinois 62706

Dear Governor Quinn:

Individuals with developmental disabilities who qualify for Intermediate Care Facilities for Persons with Mental Retardation (ICFs/MR) have a legal right to access and to stay at those facilities as long as they remain eligible and choose to do so, and thus they have a right to consider ICFs/MR their permanent home. In Illinois, State Operated Developmental Centers (SODCs) and private ICFs for persons with developmental disabilities (ICFs/DD) are the State equivalent of ICFs/MR, subject to federal certification.

In a recent report by your appointee, Anne Shannon, in which she recommended closure of the Howe Developmental Center, two significant issues were raised, and though couched in Howe details, were made applicable to all ICFs/MR. On these issues, the report's conclusions lack legal basis and need correction.

The report proposes: 1) the role of ICFs/MR is transitional; guardians are misguided in believing that they are permanent residences; and 2) guardians' choice for continued residence is attributable to guardians' failure (due to lack of education or options) to make transition decisions.

*"Some parents/guardians believe that Howe is a permanent residence. By definition, Howe Developmental Center is an Intermediate Care Facility (ICF). This means that Howe's role is to prepare residents for a transition to the least restrictive environment.*

*"Approximately half of the Howe residents are non-verbal, so parents/guardians make the transition decisions. If no decision is made, then Howe becomes a permanent residence.*

*"Some family members have not had the opportunity to be trained in their roles, responsibilities, and rights as well as residents rights.*

*Intermediate Care Facility [recommendation]*

*Educate parents/guardians that SODCs such as Howe are transitional facilities that, by definition, were never intended to be permanent residences."- Anne M. Shannon "Howe Developmental Center ('Howe')-Final Report."*

In fact, when guardians initially make or annually renew their choice of an SODC or ICF/DD for their legally incompetent, (not necessarily "non-verbal") wards, they are exercising treasured and enforceable legal rights. ICFs/MR are subject to federal rules and definitions:

**. ICF/MR (in Illinois, these include SODCs and ICFs/DD) is federally defined in the Medicaid Act by level of care, not duration of treatment:**

The term "transitional" is not used in the definition of ICF/MR. The Medicaid Act defines an ICF/MR as an intermediate care facility for mentally retarded persons where its "primary purpose ... is to provide health or rehabilitative services" and the individual "is receiving active treatment under such a program." 42 U.S.C. § 1396d(d).

**. Right to access ICFs/MR is an entitlement:**

Participation by states in the Medicaid program is voluntary; however, if a state elects to provide certain services, the state's provision of those services is "mandatory upon them." 42 U.S.C. §1396a(a)(1).

If a state elects in its Medicaid plan (as Illinois does) to offer qualified individuals services in an ICF/MR, it **must** provide that "all individuals wishing to make application under the plan shall have the opportunity to do so, and that such assistance shall be furnished with reasonable promptness to all eligible individuals." 42 U.S.C. § 1396a(a)(8).

**. Right to ICF/MR services is legally enforceable:**

The State must provide Medicaid services that it has agreed to provide to eligible individuals with "reasonable promptness." The right to ICF/MR services has already been tested in Federal District and Appellate Courts in Florida. In *Doe v. Chiles*, 136 F.3d 709 (1998) the State of Florida argued that ICF/MR services are an optional Medicaid program. The Eleventh Circuit rejected the argument, noting that "even when a state elects to provide an optional service, that service becomes part of the state Medicaid plan and is subject to the requirements of federal law." *Id* at 721. (<http://lw.bna.com/lw/19980317/965144.htm>)

**. The Home and Community Based Waiver is OPTIONAL, NOT MANDATORY, and cannot be imposed on an individual who qualifies for and chooses an ICF/MR. In fact, the HCBS waiver will not be granted and may be revoked unless the state offers ICF/MR services to those who qualify.**

\*The Medicaid Act provides that the Home and Community Based Service waiver "shall not be granted" to states unless the state provides satisfactory assurances that "such individuals who are determined to be likely to require the level of care provided in a hospital, nursing facility or intermediate care facility for the mentally retarded are informed of the feasible alternatives, if available under the waiver, at the choice of such individuals, to the provision of inpatient hospital, nursing facility services or services in an intermediate care facility for the mentally retarded." 42 U.S.C. § 1396n(c)(2)(C).

\*CMS Regulations implementing this law stipulate that "CMS will not grant a waiver...and may terminate a waiver already granted" unless a state provides certain "satisfactory assurances" including assurances that "the recipient or his or her legal representative will be 1) Informed of any feasible alternatives available under the waiver, and 2) Given the choice of either institutional or home and community-based services." 42 C.F.R. § 441.302(d).

\*Illinois Administrative Code provides that "[i]ndividuals or guardians shall be given the choice of receiving State-operated developmental center, community ICF/MR or Medicaid home and community-based services." 59 Ill. Adm. Code.120.150(c).

**. Right to choose to remain indefinitely in ICF/MR services is protected by the Supreme Court decision in Olmstead v. L.C.**

"nothing in the ADA 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." 119 S. Ct. at 2187, 17.

**Conclusion: Individuals' SODC or ICF/DD homes are permanent and their rights to them enforceable under federal law when:**

- 1) the individual remains eligible, and
- 2) the individual chooses to remain.

Over the past several years, there seems to have been a growing belief, both in the Executive Branch and the General Assembly, that ICFs/MR are an outmoded service model that the State can simply phase out in favor of the HCBS waiver model. That belief is not consistent with federal law. It is also not consistent with the needs of Illinois citizens with developmental disabilities.

Sincerely,

The Undersigned Organizations Concerned for the Rights of Individuals Receiving Services in Illinois' SODCs and ICFs/DD:

Voice of the Retarded (VOR)  
Illinois League of Advocates for the Developmentally Disabled (IL-ADD)  
Misericordia  
Mount St. Joseph Association  
Kankakee Association for the Mentally Retarded (Shapiro Family Association)  
Parents and Friends of Ludeman Center  
Beverly Farm Association  
Children's Habilitation Center  
WDC-ARC (Kiley Family Association)  
Center for DD Advocacy and Community Supports, "The Center"  
AFSCME  
Dixon Association for Retarded Citizens (Mabley Family Association)  
Marklund  
Park Lawn Association  
Fox Center Family and Friends  
Friends of the Jacksonville Developmentally Disabled  
Howe Family and Friends Association  
Little Angels  
Murray Parents Association, Inc.

Walter Lawson Children's Home  
Friends of Choate  
Achievement Unlimited, Inc.  
Community Living Options, Inc.  
Concepts Plus, Inc.  
Frances House, Inc.  
Pinnacle Opportunities, Inc.  
Pioneer Concepts, Inc.  
Community Residential Centers, Inc.  
LPC Supports Services, LLC  
RFMS, Inc.

## **STATE NEWS**

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### **2. MICHIGAN: Medicaid patients sue over dental care**

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Detroit Free Press  
By DAWSON BELL  
FREE PRESS LANSING BUREAU  
Oct. 29, 2009

A decision made earlier this year to end state support for dental services under Michigan's Medicaid program is being challenged in a federal class action, a lawyer representing patients said Thursday.

Lansing lawyer Gary Gordon said state officials acted improperly when they cut off reimbursements for 400,000 Medicaid patients as the state budget picture worsened in July. The move jeopardizes the health of recipients and ultimately, will be counterproductive as patients become sicker before seeking treatment in expensive emergency rooms, Gordon said.

Michigan lost about \$16 million in federal matching money when it discontinued its \$5 million-a-year contribution, he said.

Although states are not required to cover dental care under federal Medicaid rules, it is improper to drop the services without providing the federal government with formal notification, which Michigan has not done, Gordon said.

A spokesman for the state Medicaid program was not available for comment.

The lawsuit was filed Wednesday in U.S. District Court for the Western District of Michigan in Grand Rapids.

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### **3. MICHIGAN: RELATED NEWS: Northern Michigan woman's death raises calls to restore adult Medicaid dental benefits**

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By Kyla King, The Grand Rapids Press  
October 22, 2009

West Michigan dentists and mental health advocates are calling on state officials to restore adult Medicaid dental benefits eliminated earlier this year. The push comes after a severely mentally impaired Alpena County woman died this week, reportedly when an infection in her mouth went untreated.

"It's a serious, serious issue," said Dr. John Vander Kolk, dental director at Health Intervention Services, a Burton Heights clinic that provides affordable dental care to the working poor.

"I'm sure we've had deaths in Grand Rapids due to dental infection, even as recently as this year, but those are hard to document because of (privacy) laws," he said.

Dr. Douglas Klein, president of the West Michigan District Dental Society, said news of the woman's death stunned those in his field.

"We strongly believe this is an example of why the state of Michigan must restore Medicaid adult dental benefits," he said.

The woman, who has not been identified, lived in a group home and was treated at a dental clinic in Cheyboygan County for infected teeth, said Dr. Tom Veryser, executive director of the nonprofit Michigan Community Dental Clinics, whose agency operates the clinic.

"When this came across my desk, I almost flipped out because my worst fear has been realized, and it's one of the most vulnerable populations," he said.

Because the woman was developmentally disabled, he said, she needed to be hospitalized and sedated for the procedure. Veryser said dentists at the clinic were going to donate their services, but Medicaid coverage was needed to cover the \$5,000 in hospital costs.

The patient was scheduled for surgery June 26 but was sent home by the anesthesiologist because of fluid in her lungs, he said. The procedure was rescheduled, but adult dental Medicaid benefits were cut July 1, following an executive order by Gov. Jennifer Granholm.

Veryser said the patient died as hospital staff and clinic doctors were working to get medical justification for the procedure from an oncologist, who determined the woman's declining health and elevated white blood cell count was caused by infected teeth.

"Had the system not been interrupted, this lady would have been treated in the hospital in July and we wouldn't have had to go through a (medical) justification process," Veryser said.

Michigan Community Health Department spokeswoman Kelly Niebel said the state is looking into the report to determine what happened.

"We learned of this on Monday. We have very limited information," Niebel said. "It sounds like

a tragic situation."

Gov. Granholm's spokeswoman, Liz Boyd, said the governor cannot appropriate money into the state budget and "is in a fight" to increase Medicaid funding in the form of a physician tax that will net the state hundreds of millions of dollars to serve the poor, the disabled, the elderly and our children.

"While DCH awaits official confirmation on the details of this tragedy, it underscores the need in our state and why Gov. Granholm will continue to fight for increased funding," Boyd said.

News of the woman's death prompted a citizens group called Progress Michigan to demand Senate Republicans support the Granholm-backed tax on doctor's services to fund Medicaid.

"You know, people always say that you can't put a price on a human life, but in this case, you can - \$5,000," said David Holtz, executive director of Progress Michigan, referring to the cost of the woman's hospital stay Medicaid declined to cover. "This woman would still be alive if her coverage had been intact."

## **VOR and YOU**

### **4. Not a VOR member? Consider joining VOR today**

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That is one of the great things about e-mail - it is easily forwarded. We encourage our members to share VOR's e-mail communications because it allows VOR to reach (indirectly) many more advocates than we could otherwise.

If you are one of the lucky recipients of VOR's E-Mail Updates and other e-mail communication but are not a member, please consider joining VOR today. Membership is only \$25/year. You receive our information. You know we do good work. Please consider showing your support and appreciation with a VOR membership.

A membership form can be found below or at [VOR's Website](#).

## **THANK YOU!!**

### **5. Your Membership and Gifts Make a Difference!!**

[VOR](#) is the only national advocacy organization that expressly opposes efforts to eliminate the facility option while also supporting expansion of quality community programs. VOR advocates that final determination of what is appropriate depends on the unique abilities, needs and desires of each individual, with the input of family guardians where necessary and appropriate.

Thank you for your support!

(Consider giving a VOR membership as a Holiday Gift!)

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**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!

You may pay by check or credit card

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