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 at721. (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.