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ANNIVERSARY
Speaking out for people with intellectual & developmental disabilities

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July 25, 2013

The Honorable Marvin E. Aspen
U.S. District Court Northern District of Illinois
Everett McKinley Dirksen United States Courthouse
219 South Dearborn Street
Chicago, IL 60604

Re: Support for Murray Developmental Center

Dear Judge Aspen,

I represent VOR, a national organization advocating for high quality care and human rights for all persons with intellectual and developmental disabilities (I/DD).

The Illinois League of Advocates for the Developmentally Disabled (IL-ADD) and the Murray Parents Association (MPA) are organizational affiliates of VOR, and several individual named plaintiffs in IL-ADD et al. v. Illinois Department of Human Services et al. (Case No. 13 C 01300) are individual VOR members.

On their behalf, VOR offers our support for the need for Murray Developmental Center, and the remaining State Operated Developmental Centers (SODCs) in Illinois, as part of the array of service options for Illinois' citizens with I/DD. As federally-licensed Intermediate Care Facilities for Individuals with Intellectual Disabilities (ICFs/IID), Murray and SODCs provide a standard of care and access to specialized supports that are not routinely available in smaller settings.

VOR appreciates this opportunity to offer our perspective with regard to the need for an array of long-term services and supports that are responsive to the needs of *all* people with disabilities. VOR recognizes that "equitable" does not mean identical when dealing with human needs. While we support the need for expanded quality community-based options, we object strongly to the notion that eliminating quality homes like Murray Developmental Center will somehow "rebalance" the service system. In our view, equitable does not mean identical. Too often the quest for "rebalancing" neglects person-centered supports in an unreasonable, and potentially dangerous, quest for "sameness." The human condition is not that convenient. Service options must necessarily vary and be responsive to varying needs.

Most importantly, VOR trusts that families (often court-appointed legal guardians) know their loved ones best. No one would question the right of parents of minor children to make health care and support decisions, yet time and again, the decisions and input of family members of adults with profound I/DD – some of whom have the cognitive ability of infants and toddlers – are ignored and trumped by state officials, federal lawyers, and other advocacy organizations who have never even met all affected Murray residents.

Families have reason to be concerned. There are well-documented tragedies in small settings serving disabled individuals in Illinois and around the country due to poorly trained staff and lack of access to specialized care and lack of oversight.

> "I write to you today to request that you undertake an immediate investigation into the alarming number of deaths and cases of abuse of developmentally disabled individuals in group homes. In particular, I would like you to focus on the prevalence of preventable deaths at privately run group homes across this nation and the widespread privatization of our delivery system." (U.S. Senator Chris Murphy, Letter to the U.S. Department of Health and Human Services' Office of Inspector General (March 4, 2013)) (*see also*, Widespread Abuse, Neglect and Death in Small Settings Serving People with Intellectual Disabilities, 2013).

"If this were your family member, what would you do?"

VOR members have asked this question of public officials around the country. The question puts the debate in a human context which transcends ideology and alleged cost savings. Murray Developmental Center is a Medicaid licensed option. No one is suggesting that it is providing bad care. The allegations range from it costs too much to a claim that its residents will more "integrated" in smaller settings. True "integration" is debatable and costs will not be saved if all necessary supports are provided in the community.[1]

For additional background I've attached testimony that VOR submitted to the Illinois Legislature in 2011. This testimony covers the people, the law, quality and costs. At the end of the day, however, we view the insights and input of families as paramount.

You have heard from families who view Murray as a treasure which provides their profoundly disabled loved ones with life-sustaining, highly skilled and compassionate care – all while enjoying "inclusion" in their surrounding community. They are the experts. Thank you for trusting them.

Sincerely,

Ann S. Knighton

[1] Walsh, Kevin K., et al., "Cost Comparisons of Community and Institutional Residential Settings: Historical Review of Selected Research," Mental Retardation, Volume 41, Number 2: 103-122, April 2003) ("Findings do not support the unqualified position that community settings are less expensive than are institutions and suggest that staffing issues play a major role in any cost differences that are identified") (see also, Illinois League of Advocates, "Can The Community Provide HIGH NEEDS INDIVIDUALS Essential Services Comparable to SODC Services At Significantly Reduced Cost: BRB Case Study," October 17, 2011, http://www.vor.net/images/ILADDCostComparson.pdf)

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November 7, 2011

The Honorable Members of the Illinois State Legislature
State House
Springfield, Illinois

Re: VOR's written comments for consideration by Illinois Legislators in support of a full array of residential options, including State Operated Developmental Centers (SODCs). Saving Mabley, Jacksonville and all SODCs is cost effective and consistent with state and federal law.

Dear Illinois Legislators:

I represent VOR, a national advocacy organization for persons with intellectual and developmental disabilities (ID/DD) and their families and legal guardians.

VOR offers a unique perspective: VOR is the only national advocacy organization that supports the provision of a full spectrum of care options for individuals with ID/DD, from own home and smaller homes to federally-licensed larger residential homes (ICFs/MR), including State Operated Developmental Centers (SODCs).

VOR's respect for families as experts in their loved ones care also sets VOR apart from other national groups. The majority of individuals for whom we advocate that receive ICF/MR care have profound intellectual disabilities with the cognitive ability of infants or young toddlers. They rely on their families to ensure they receive high quality care. Their families, many of whom are also court-appointed legal guardians, know them best and have no ulterior motives other than their well-being.

As our written comments will explain in detail, VOR supports the expansion of desperately needed "community"-based options, but not at the expense of equally necessary developmental centers (licensed Intermediate Care Facilities for Persons with Mental Retardation, ICFs/MR).

To meet the diverse needs of the ID/DD population, one size does not fit all. Illinois can and should have it both ways.

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I. Summary of VOR Position and Recommendations

The catalysts which support closure are based on faulty assumptions relating to cost, quality and the law.

Developmental centers provide cost-effective, specialized services and care not available elsewhere for the State's most disabled citizens. Current census numbers and downsizing do not reflect demand. Individuals who may benefit from developmental center supports are not even presented with the developmental center as service option unless court ordered or referred from another provider who could not handle the individual.

True demand and need for developmental center care cannot be known because state policy deflects admissions and requires transfers based on arbitrary quotas which have the net result of reducing census. Nearly all residents and their families overwhelmingly support continued developmental center supports and object to transition from the center. With such a high satisfaction rate, how can an arbitrary quota which requires transitions be reconciled with federal laws regarding resident/guardian choice and ***Individual*** Habilitation Plans (IHPs)? (See "The Law Requires Residential Choice," p. 6, below).

The lack of community capacity is also well documented. Long waiting lists and recent budget cuts have further decimated the community infrastructure, cutting some programs (e.g., the Community Professional Supports and Training program) and making expansion of life-sustaining health care and other specialized supports out of reach.

Recommendations

1. Illinois is strongly urged to arrange for an independent cost comparison of developmental center versus community-based care. Such a study must take into account all costs for each setting[2], the cost to develop presently inadequate community programs and infrastructure; consider the impact that closed admissions have had on the cost-effectiveness of developmental centers (which are artificially under-utilized), and take into account the revenues that will be lost with any developmental center closure.

2. Illinois is strongly urged to arrange for an independent outcome study that considers the present well-being of former developmental center residents who have been transferred to the community, especially within the last 5 years. Before displacing current ICF/MR residents, this Illinois should consider any lessons learned from prior closings, as well as the impact on individuals who have more recently displaced from developmental centers due to downsizing. An outcome study, to focus on individual outcomes, such as mortality, access to health care and other necessary services, trends associated with 911 calls and emergency room utilization, staffing turnover and more, could be built into the required review of community capacity.

[2] Although it is often assumed that smaller residential settings cost less, ***very*** often this comparison is based on the all-inclusive cost of developmental center supports and a community cost figure that excludes significant line items such as room-and-board, transportation, health care, day programming and more. *See*, "Cost Comparisons of Community and Institutional Residential Settings: Historical Review of Selected Research," *Mental Retardation*, Vol. 41, No. 2: 103-122 (April 2003) (detailed on page 4 of this testimony and *Attachment A*).

3. **Expand, don't eliminate, service options available to citizens with ID/DD. Thousands of people are languishing without services.** Some of these individuals would benefit from developmental center supports if provided that option. Given the state's budget crisis, the lack of community infrastructure, current needs, and the likelihood that costs will not be saved, Illinois is urged to embrace a forward-thinking solution that would allow admissions to developmental centers based on individual choice and need, while also making the specialized services at developmental centers available to non-residents. Offering outpatient care to non-residents is a proven model already in place in several states. These "Community Resource Centers" (CRC) have been shown to be a cost-effective way to provide not otherwise available professional services to community-based individuals. Because the CRC model relies on an existing infrastructure, it is cost-effective and helps keep individuals in community-settings well-cared for and out of (more expensive) crisis situations.

II. Rationale and Background

VOR's recommendations are supported by the following background information and rationale.

1. The People Being Served

ICFs/MR are often the best, most cost-effective way to meet the needs of the most vulnerable of the population with intellectual and developmental disabilities.

Residents of ICFs/MR are among the neediest, most fragile and most disabled members of our society. They need support in every aspect of life including walking, communicating, bathing, eating and toileting.

Nationally, nearly 75% (74.5%) of all ICF/MR residents experience severe and profound intellectual disabilities; they also endure multiple disabilities, chronic medical conditions and/or behavioral challenges. Many also have seizure disorders, behavior problems, mental illness, are visually-impaired or hearing-impaired, or have a combination of these conditions[3].

In Illinois, 75.8% of developmental center residents have severe or profound intellectual disabilities, with 64.9% having two or more additional disabling conditions such as cerebral palsy, blindness, hearing impairments, seizure disorders, psychiatric disorders, etc.[4] A significant number of residents cannot communicate "basic desires verbally" (55.2%) and cannot "understand simple verbal requests" (29.5%) [5]. Many developmental center residents also need assistance walking (27.5%), transferring (27.3%), eating (44%), dressing (39.3%) or toileting (53.3%) [6].

In Illinois and nationally residents of ICFs/MR are our most fragile citizens. Compassionate, specialized care provided in ICFs/MR homes – homes specially designed for these complex needs – is a good human and fiscal investment. ***Where*** will these individuals receive life-sustaining services and ***at what cost*** are two questions that must be answered before a decision is made to displace ICF/MR residents from their current homes.

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[3] "Residential Services for Persons with Developmental Disabilities: Status and Trends Through 2008,"Research and Training Center on Community Living Institute on Community Integration/UCEDD, College of Education and Human Development University of Minnesota (2009) (http://rtc.umn.edu/docs/risp2008.pdf)
[4] Id.
[5] Id.
[6] Id.

VOR Recommendation

1. Illinois is strongly urged to arrange for an independent cost comparison of developmental center v. "community"-based care. Such a study must take into account all costs for each setting, the cost to develop presently inadequate community programs and infrastructure; consider the impact that closed admissions have had on the cost-effectiveness of developmental centers (which are artificially under-utilized), and take into account the revenues that will be lost with any developmental center closure.

2. Costs

a. Developmental Centers provide cost effective care; Conduct accurate, independent cost comparisons

Common-sense says that it is more cost effective to serve individuals with complex, high cost needs in one location than in scattered locations. The care provided in developmental centers is not only cost effective, but also compassionate, consistent, and experienced. In contrast to high turnover of direct care staff in community settings, and the often non-existent professional care, many of the developmental center direct care and professional staff have worked for the developmental centers for many, many years.

The widely-held belief that it always costs less to care for people with intellectual and developmental disabilities in smaller homes rather than in developmental centers **is not true** for people with the most severe disabilities, according to peer-reviewed study published in *Mental Retardation*, a journal by the American Association on Mental Retardation:

"From the studies reviewed here, it is clear that large savings are not possible within the field of developmental disabilities by shifting from institutional to community placements."[7]

The study details several cost factors that are often overlooked by policymakers and advocates, including, but not limited to:

- **Level of disability**: The failure to adjust for the different levels of disability of the people included in the studies skews the results. Facility residents are the most needy, most vulnerable and most costly of all Medicaid recipients, regardless of service setting. In Illinois, 75.8% of developmental center residents are persons with severe and profound intellectual and other complex disabilities.

- **Aggregate costs and cost shifting:** When individuals are moved from facility-based to community placements, costs shift from the all-encompassing facility care budget to a community services budget that draws from multiple public welfare funding sources for housing, food (e.g., food stamps), transportation, and health care costs. Often only the housing costs are considered in community v. facility cost comparisons. The result is an incomplete look at the true costs of serving the individuals, and a false claim of taxpayer savings.

- **Staffing:** The failure to consider the relevance of lower staffing costs in the community also impacts quality outcomes. If federal initiatives to enhance wages for community-based direct care workers are successful community costs will increase.

[7] Kevin K. Walsh, Theodore A. Kastner, and Regina Gentlesk Green, "Cost Comparisons of Community and Institutional Residential Settings: Historical Review of Selected Research," *Mental Retardation*, Vol. 41, No. 2: 103-122 (April 2003). An updated summary of this study by the primary researcher is attached (*Attachment A*).

The dogmatic belief that placement in the community is always cheaper has resulted in a woefully under-funded community system that is not at all prepared to care for the complex needs of most of the people now residing in larger, specialized facilities, or the thousands of people waiting for services. This study gives state lawmakers the data they need to determine accurate costs.

b. The potential for lost revenues

In addition to the potential loss of federal Medicaid funding, lost state and local revenues is another often-overlooked cost of closure. Consider this testimony (excerpts) by a representative of the Topeka, Kansas Chamber of Commerce:

> "We are being told that moving residents out of KNI [a state operated ICF/MR] will save the state money. Yet, we have those who indicate quality housing and services for clients with such significant needs are not currently available. To replicate what now exists at KNI will certainly be very costly.
>
> "Most residents have lived in their KNI home for many years and relate to those who care for them as family members. Deliberations to force them from their home, is devastating to their families and guardians. We understand none of the committees reviewing this issue have been provided a list of facilities with available space, appropriate specialized equipment and quality trained staff for KNI residents? We are not convinced such housing is readily available here or throughout the state and believe this proposal will only result in cost shifts to provide what is already existing at KNI, we doubt there will be any cost savings. . . .
>
> "The Topeka Chamber commissioned an economic impact analysis of KNI on Topeka, for the State Closure Commission in 2009. This study was completed by Impact Data Source, Austin, TX. It is attached to my testimony[8].
>
> "KNI had a significant impact on the Topeka area economy during FY 2010. KNI's revenues and expenditures and its employees and their salaries provide direct economic activity. In addition, this activity ripples through the area's economy supporting indirect benefits including sales at local businesses and organizations, as well as indirect jobs and salaries . . . In total the economic impact of KNI in FY 2010 was $66 million . . .
>
> "If the motive for closing KNI is saving the state dollars, we respectfully ask your very careful consideration of whether there are real cost savings or cost shifts. We ask that you listen to those who know the residents of KNI the best – their families, care-givers and the medical community. The Greater Topeka Chamber of Commerce urges your decision to be that KNI [ICF/MR] and support services continue to serve our State's most needy." (March 2, 2011, Testimony by Christy Caldwell, Vice President Government Relations, Greater Topeka Chamber of Commerce; complete testimony available here: http://vor.net/images/ChamberTestimonyKNIClosure.pdf).

See also, **Illinois: Closing center would cost $47 million, report finds (The State Journal-Register, September 23, 2011 at** http://www.sj-r.com/top-stories/x26164536/Closing-JDC-would-cost-Morgan-County-47-million-report-finds.

[8] "A Report of the Economic Impact During Fiscal Year 2010 of the Kansas Neurological Institute in Topeka, Kansas" (September 19, 2009), available at http://vor.net/images/KNI_Impact_Report1.pdf.

3. The Law Requires Choice

a. The Americans with Disabilities Act (ADA) and Olmstead[9]

Despite propaganda to the contrary, the law, including the landmark Olmstead decision, does not require that *all* people with disabilities be served in community-based settings, nor does Olmstead require that ICFs/MR be closed.

Rather, in its Olmstead decision, the U.S. Supreme Court considered the ADA's "integration mandate" and very expressly concluded that "integration" (community placement) is only required when an individual's needs can be safely served in a non-ICF/MR setting and when transfer from the ICF/MR is not opposed by the individual (Olmstead v. L.C., 119 S. Ct. 2176, 2181 (1999)).

The Supreme Court even cautioned against taking its holding too far:

> "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." Olmstead v, L.C, 119 S. Ct. 2176, 2187 (1999).

Consistently, the plurality opinion noted:

> "As already observed [by the majority], the ADA is not reasonably read to impel States to phase out institutions, placing patients in need of close care at risk... 'Each disabled person is entitled to treatment in the most integrated setting possible for that person — recognizing on a case-by-case basis, that setting may be an institution' [quoting VOR's *Amici Curiae* brief]." 119 S. Ct. at 2189 (*plurality opinion*).

Federal courts since Olmstead have recognized its "Choice Mandate":

> "Thus, the argument made by Arc and the United States [*Department of Justice*] who filed regarding the risk of institutionalization fails to account for a key principle in the Olmstead decision: personal choice. And here, where more residents desire to remain in institutional care than the new facility can provide for, there is little to no risk of institutionalization for those whose needs do not require it and who do not desire it." Arc of Virginia v. Kaine (December 2009)[10]; see also, People First of Tennessee v. Clover Bottom Developmental Center (May 2010) ("The intersection of citizen choice and the ADA was addressed by the Supreme Court in *Olmstead v. L.C.* . . . [T]here is no federal requirement under the ADA that community-based treatment must be imposed on citizens who do not desire it.")[11]

A recent federal court decision further emphasized the importance of the respecting the input of ICF/MR residents and their families as the input that matters most. The court went as to chastise the United States Department of Justice, which brought the lawsuit in its own name, for pursuing a cause without a plaintiff:

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[9] The Olmstead decision can be found at http://supct.law.cornell.edu/supct/pdf/98-536P.ZS; and additional Olmstead resources can be found at http://www.vor.net/olmstead_resources.htm.

[10] For full decision: http://www.vor.net/images/SEVTCDecision.pdf

[11] For full decision: http://www.vor.net/images/CloverBottomChoiceDecision.pdf

> "Most lawsuits are brought by persons who believe their rights have been violated. Not this one . . . All or nearly all of those residents have parents or guardians who have the power to assert the legal rights of their children or wards. Those parents and guardians, so far as the record shows, oppose the claims of the United States. Thus, the United States [Department of Justice] is in the odd position of asserting that certain persons' rights have been and are being violated while those persons – through their parents and guardians disagree." United States v. Arkansas (June 2011)[12]

b. Medicaid Law

The receipt of federal Medicaid funding is contingent upon ***a state*** offering the choice of ICFs/MR or Home and Community Based Services (HCBS) waivers.

A Medicaid HCBS waiver shall not be granted 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).

When a recipient is determined to be likely to require the level of care provided in an ICF/MR, 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

The State agency ***must*** furnish CMS with sufficient information to support the assurances required by §441.302, including its "plan for informing eligible recipients of the feasible alternatives . . . institutional services or home and community-based services." 42 C.F.R. §441.303(d).

Likewise, federal law relating to Individual Habilitation Plans (IHPs) for residents of Medicaid Intermediate Care Facilities for Persons with Intellectual Disabilities (ICFs/MR) ***requires*** individualized plans.

Simply stated, Medicaid law requires that Illinois' ICF/MR (developmental center) residents be granted a choice between an ICF/MR and HCBS waiver alternatives.

[12] For full decision: http://www.vor.net/images/ArkansasDecision.pdf

4. Quality and Outcomes

VOR Recommendation

2. Illinois is strongly urged to arrange for an independent outcome study that considers the present well-being of former developmental center residents who have been transferred to the community, especially within the last 5 years. Before displacing current ICF/MR residents, this Illinois should consider any lessons learned from prior closings, as well as the impact on individuals who have more recently displaced from developmental centers due to downsizing. An outcome study, to focus on individual outcomes, such as mortality, access to health care and other necessary services, trends associated with 911 calls and emergency room utilization, staffing turnover and more, could be built into the required review of community capacity.

Quality care is not a function of where one lives but of the involvement of relatives and guardians, the skills and commitment of the staff and proper oversight.

The cause of documented, compromised quality in community-based settings for people with intellectual and developmental disabilities is generally linked to the rapid expansion of community programs over the past decade; inadequate access to health care; the lack of adequate staff training and competency (attributed to low wages and qualifications); the lack of state and federal oversight; and the lack of adequate funding.

These concerns are widespread. In at least 30 states (including Illinois[13]) and the District of Columbia, reports of ***systemic*** abuse, neglect and death have appeared in newspapers, state audits, and scholarly journal articles (http://vor.net/images/AbuseandNeglect.pdf) Congress, the U.S. Surgeon General, the General Accountability Office and CMS have also cited serious concerns regarding compromised quality in community settings. For example, citing lack of access to necessary health care, the U.S. Surgeon General noted in 2002, "Compared with other populations, adults, adolescents, and children with mental retardation experience poorer health and more difficulty in finding, getting to, and paying for appropriate health care." Financial exploitation was the subject of a 1993 House Committee on Small Business, released by then-Chair Ron Wyden: "Increasingly, millions of Americans with these life-long handicaps are at risk from poor quality care, questionable and even criminal management practices by service providers, and lackluster monitoring by public health and welfare agencies."

While similar problems do occur in ICFs/MR, state and federal scrutiny regarding ICF/MR care guards against long-term, systemic problems. CMS holds ICFs/MR to 378 specific standards ("Conditions of Participation") annually. In contrast, HCBS waiver programs are reviewed only every 3-5 years and are **not** subject to uniform quality assurance standards (***see***, **Attachment B**). While there are good community programs, there are many others that fail to provide high quality care. The current system of oversight often fails to identify these "bad apples" until tragedy occurs.

[13] As recently as May 2011, the *Associated Press* reported that more than 130 cases of abuse and neglect were investigated and confirmed in group homes for adults in 2010, a 33 percent increase compared to 2006, according to government documents obtained by *AP*. The reports of mistreatment and outright cruelty at the hands of low-wage workers with scant supervision, illustrate a mostly overlooked problem in Illinois.

VOR Recommendation

3. Expand, don't eliminate, service options available to state citizens with ID/DD. Thousands of people in Illinois are languishing without services. Some of these individuals would benefit from developmental center supports if provided that option. Given the state's budget crisis, the lack of community infrastructure, current needs, and the likelihood that costs will not be saved, Illinois is urged to embrace a forward-thinking solution that would allow admissions to developmental centers based on individual choice and need, while also making the specialized services at developmental centers available to non-residents. Offering outpatient care to non-residents is a proven model already in place in several states. These "Community Resource Centers" (CRC) have been shown to be a cost-effective way to provide not otherwise available professional services to community-based individuals. Because the CRC model relies on an existing infrastructure, it is cost-effective and helps keep individuals in community-settings well-cared for and out of (more expensive) crisis situations.

5. An Ideal Balance: Admissions and Community Resource Centers

Across the country, individuals with intellectual and developmental disabilities who reside at home or in community-based services face long waits for needed services, such as health care, dental care, OT/PT, and even wheel chair adjustments. Illinois is no exception: thousands of individuals await services. Many of these people simply go without.

It doesn't have to be that way.

VOR recommends the expansion of specialty out-patient clinics (Community Resource Centers) situated at Illinois' existing Developmental Centers, while also allowing admissions to developmental centers for individuals who choose and require this level of care.

Presently, the State's Developmental Centers are an undervalued resource. Closed admissions have resulted in higher-than-necessary waiting lists and artificially higher costs. Developmental centers have extensive, onsite specialized, professional services that are not available in most Illinois communities **(*see* Attachment C)**.

Allowing admissions ***and*** making the developmental center's specialized professional supports available to nonresidents, would have the effect of making the developmental centers more cost effective, while also ensuring successful community placements. Costly crises that occur when individuals don't have access to health care (e.g., 911 calls, emergency room visits, dental surgeries v. preventative care) could be avoided by allowing non-residents to access the center's professional services as out-patients.

Community Resource Centers are a proven model in several states.[14] Attached is a compelling letter from the Dr. Matt Holder, Director of a Community Resource Center in Kentucky, the Underwood and Lee Clinic. Situated at Kentucky's Hazelwood ICF/MR, the clinic opened its doors a decade ago and now serves more than 1,000 individuals with intellectual and developmental disabilities from throughout Kentucky. Demand is significant; major expansion is in process and when completed (2012), the clinic's capacity will quadruple **(*see*, Attachment D).**

State lawmakers are encouraged to speak directly with Dr. Holder. Another helpful resource is Dr. Mark Diorio, Director of the Northern Virginia Training Center, a state operated ICF/MR that has a long-standing, successful Community Resource Center on site.

[14] Examples of Community Resource Centers can be found in Virginia, Massachusetts, Kentucky, Washington State, Missouri, and Florida. In New Jersey, a component of the model - training – is in place at Hunterdon Developmental Center where students preparing for a career in healthcare (nursing, physicians and dentists) receive onsite training opportunities working with people with disabilities.

III. Conclusion

Thank you for this opportunity to present our recommendations. Community expansion is desperately needed. Community expansion, however, must not take place on the backs of the fragile residents receiving life-sustaining supports in state developmental centers (Medicaid licensed ICFs/MR).

Rather than eliminating developmental centers and displacing people from their *homes*, consider the opportunities that the developmental centers offer to assist in delivering high quality care to more people at less cost.

Thank you for your thoughtful consideration and your compassionate leadership. Please support a full spectrum of services and supports, including State-Operated Developmental Centers, to meet the diverse needs of all Illinois citizens with intellectual and developmental disabilities. For more information, please contact VOR's Director of Government Affairs and Advocacy, Tamie Hopp at thopp@vor.net or 877-399-4867.

Sincerely,

Julie Huso
VOR Executive Director

ATTACHMENT A

(For a copy of this 2003 study contact thopp@vor.net)

UPDATE

January, 2009

Cost Comparisons of Community and Institutional Residential Settings: Historical Review of Selected Research

Kevin K. Walsh, Theodore A. Kastner, and Regina Gentlesk Green
Mental Retardation, Volume 41, Number 2: 103-122, April 2003

In the 2003 article noted above a review of selected literature was undertaken to determine the validity of institutional vs. community cost comparisons. A number of methodological problems were identified in the literature reviewed that compromised much of the earlier research on the topic. Additionally, a number of considerations were outlined – *source of funds, cost shifting, cost variation, staffing,* and *case mix* – that need to be taken into account when such comparisons are undertaken.

The question has arisen whether the conclusion of this 2003 review, that large savings are not possible within the field of developmental disabilities by shifting from institutional to community settings, remains current.

For the reasons explained below, we find that the 2003 article continues to be valid in 2009 and beyond. That is, cost savings at the macro level are relatively minor when institutional settings are closed and, if there are any at all, they are likely due to staffing costs when comparing state and private caregivers.

As such, the study will continue to be useful in policy discussions in states.
Several factors point to why the study's conclusions remain valid in 2009:

Review Article. As a *review* article, the 2003 publication does not generate new *data*; that is, it reviews previous research. Because of this, the article is more resistant to becoming outdated. Those reading the article, however, would do well to keep in mind that the studies reviewed in the article employ cost figures that existed *at the time the original research articles were published*. Therefore, while the findings and conclusions drawn in Walsh, et al. (2003) will continue to be timely, the actual cost figures may need to be adjusted to current levels.

Stability of the Components. Because the service and support landscape remains, in large part, similar in 2009 to 2003 and before, the conclusions of Walsh, et al. are likely to hold. For the most part comparisons reviewed generally compared congregate ICF/MR settings and community-based residential settings (typically group homes) funded under the Medicaid HCBS waiver. Although many states have been moving toward personal budgets and fee-for-service models, group homes continue to be a primary community residential service setting. In this way also the conclusions of the 2003 article continue to be applicable.

Stability of the Issues. As noted, the 2003 article presented descriptions of various considerations that affect cost comparisons across states. Because the structural components of the issue have remained unchanged (e.g., institutional settings, group homes) and the funding models have remained largely intact (i.e., Medicaid ICF/MR and HCBS waivers), the various factors affecting them, for the most part, remain as presented in Walsh, et al.

That is, there remains a great deal of cost variation from institutional to community settings as described in the article; cost shifting, as described in Walsh, et al., is to some extent likely to be structurally fixed in most states owing to the nature of state governments. That is, when certain costs disappear, when individuals are transferred from ICF/MR settings, it is highly likely that these costs will reappear in other state budgets (such as Medicaid). In nearly all instances, this is almost unavoidable. In short, costs don't just disappear when individuals are moved.

Based on the forgoing, it appears that the conclusions drawn in the 2003 article continue to be valid.

Kevin K. Walsh, January 23, 2009

ATTACHMENT B

Home and Community Based Services Waivers: An overview

The Home and Community-Based Services (HCBS) waiver program was established in 1981 as part of Medicaid in the Social Security Act (1915(c)). Under the HCBS waiver program, states can elect to furnish a broad array of services (excluding room and board) that may or may not be otherwise be covered by Medicaid, including case management, homemaker, home health aide, personal care, adult day health care, habilitation, and respite services. States can request permission to offer additional services. The Centers for Medicare & Medicaid Services (CMS) must grant approval of all waiver applications. The intent of the waiver is to give states the flexibility to develop and implement alternatives to institutional care for eligible populations. Eligible populations include Medicaid-eligible elderly and disabled persons, physically disabled, persons with developmental disabilities or mental retardation, or mental illness. Individuals must be shown to be eligible for institutional services (such as an Intermediate Care Facility for Persons with Mental Retardation (ICFs/MR) to be eligible for HCBS. (Source: Duckett, M.J. & Guy, M.R., *HCBS Waiver*, Health Care Financing Review (Fall 2000). Vol. 22, Number 1, pp 123-125).

Quality Assurance: ICF/MR and HCBS Compared

ICF/MR	HCBS
To be federally certified, ICFs/MR must meet 8 conditions of participation: (CoPs): Management; Client Protections; Facility Staffing; Active Treatment; Client Behavior and Facility Practices; Health Care Services; Physical Environment; and Dietetic Services. The eight CoPs comprise 378 specific standards and elements. State surveyors conduct annual onsite reviews. CMS is currently conducting "look behind" surveys of every state and public ICFs/MR to "double check" the state surveyors' findings. Serious deficiencies must be corrected within 90 days; other deficiencies must be corrected within a year. Failure to correct deficiencies results in loss of certification and loss of Medicaid funding. The Department of Justice (DOJ) also has a role in overseeing public (not private) ICFs/MR. DOJ does not have jurisdiction over community programs.	Although there is no standard HCBS program, all are required to provide CMS with the following assurances, as a condition of waiver approval: health and welfare of waiver participants; plans of care responsive to waiver participant needs; only qualified waiver providers; State eligibility assessment includes need for institutionalization; State Medicaid Agency retains administrative authority; and the State provides financial accountability **(the waiver must cost less than the institutional program).** HCBS waivers are reviewed every 3-5 years. Earlier this year, CMS refined its method of quality oversight, initiated with the release of *The Protocol* in 2000. In January 2004, CMS made mandatory the use of the *Interim Procedural Guidance* as the method for federal waiver review. The *Guidance* requires CMS staff to solicit evidence from the states as to their quality management strategy and implementation, including evidence that the statutory and regulatory assurance have been met. CMS is also revising the voluntary waiver application template and the annual report form ("372 form") to gather additional information about how states assure and improve quality.

Note of caution: The "flexibility" catch-22

The cornerstone of the HCBS waiver – state flexibility – is also its catch 22 for participants. Every 3-5 years a state has the option to renew, not renew, or change the terms of its waiver program. HCBS services must be delivered pursuant to the development of a plan of care and based upon assessed individual needs. However, because the HCBS program is an optional benefit and states have the flexibility to determine the service package, number of persons to be served, target group, etc., a participant may find themselves cut from the program or with a different mix of services than in prior years. In Mississippi, for example, an approved waiver resulted in 48,000 people being cut from the waiver program. In nearly every state, Governors are considering changes to the Medicaid program.

There is no question that the HCBS waiver program has allowed thousands of individuals to be adequately served in community-based settings. The residents remaining in our nation's ICFs/MR, however, are the most fragile and most in need of consistent, high quality, services. When considering the waiver option, individuals, families and guardians are cautioned to weigh the benefits with the costs.

ATTACHMENT C
The services people receive in licensed
Intermediate Care Facilities for Persons with Mental Retardation (ICFs/MR)

For More Information

Background and Milestones – ICFs/MR →
http://www.cms.hhs.gov/CertificationandCompliance/Downloads/ICFMR_Background.pdf

ICFs/MR: Meeting the Long Term Care Needs and Maximizing the Potential of Individuals with MR/DD: →
http://www.ihca.com/consumer/ddcare.htm#Meeting

Characteristics of Residents of Large Facilities: →
http://rtc.umn.edu/docs/risp2008.pdf (pages 33-39)

ICFs/MR as Permanent Homes: →
http://vor.net/images/stories/ICFsMR_are_home.pdf

ICFs/MR: A sampling of the comprehensive services provided to residents

Medical	**Dental**	**Behavioral psychology**	**Clinical social work**	**Dermatology**
ENT	**Gastroenterology**	**Gynecology**	**Neurology**	**Nursing**
Nutrition	**Occupational therapy**	**Physical therapy**	**Orthopedics**	**Ophthalmology**
Pharmacology	**Psychiatric**	**Podiatry**	**Pulmonology**	**Lab work**
Speech/ language therapy	**Therapeutic recreation (e.g, swimming, equestrians, etc.)**	**Vocational assessment, training and opportunities (on and off campus)**	**Wheelchair clinics/Rehab engineering**	**Assistive technology/ communication augments/ switch activation**
audiology	**Respite Services**	**Habilitation**	**Staff and Student Training (classroom/on-the-job).**	**Residential, including dormitory, group homes, private rooms, cottages, apartments.**
Direct care for activities of daily living (eating, dressing, bathing/ hygiene, toileting, mobility, etc.)	**Sensory integration/ Stimulation Room**	**Pet therapy**	**Respiratory therapist**	**QMRPs**
Family Support and Advocacy Organizations	**Active Treatment Services**	**Transportation**	**Library**	**Nutritionist/ Dieticians**
Religious services/ chapel	**Human Rights Committee**	**Cafeteria, private kitchens, Canteens**	**Restaurants and stores open to public**	**Other services not noted here**

This comprehensive assortment of federally-certified professional therapeutic, dietary, health care, recreational, and residential services is required by the neediest, most fragile, and most disabled members of our society.

Group homes – even those homes that are certified by the Centers for Medicare and Medicaid Services (CMS) – do not provide the same level of programming, with the same assortment of onsite, specialized services, as ICFs/MR.

For many ICF/MR residents, the provision of professional support and health care is required for their very survival.

ATTACHMENT D

underwood+lee
CLINIC

October 12, 2011

My name is Dr. Matthew Holder, I am writing in support of the Community Resource Center model, as recently proposed by VOR, a national advocacy organization for persons with intellectual and developmental disabilities. . I am the Chief Executive Officer of what is arguably the most successful patient care, teaching and research model of dental care designed for people with neurodevelopmental disorders (ND) in the United States, the Underwood and Lee Clinic in Louisville, Kentucky. I would like to share with you our experience in starting, maintaining, growing and transforming this clinic over the past decade.

The Community Resource Center Model is not a new concept. It has been around for over a decade. In 1999 our clinic founder, Dr. Henry Hood, first started working on the idea of building an outpatient clinic on the campus of the Hazelwood Intermediate Care Facility for Mental Retardation (ICF/MR) in Louisville. Originally, the concept was to have a medical and dental outpatient clinic focusing exclusively on adults with neurodevelopmental disorders and/or intellectual disabilities (ND/ID) living in the community. One of the benefits of the model was that existing ICF/MR infrastructure could be utilized, thereby reducing the cost of care provided.

As a concept in 1999, the Underwood and Lee clinic met some significant resistance. There was resistance from those in the state who felt that ICF/MR infrastructure was untouchable ground – that people in the community would be so repelled by the thought of setting foot on ICF/MR grounds, that the clinic would be destined to fail. There was resistance from those who had the incredibly misguided notion that community-based healthcare was adequate for this population and that a specialized clinic would only represent redundant care – after all, there were Medicare clinics and Federally Qualified Health Centers (FQHC) who were supposedly taking care of this population. There was resistance from those in the state who only examine finances. Their objection was that the cost of such care simply was not a sensible investment for the state. And of course, there was resistance from within state government itself, because what was being proposed was an unproven and untested concept.

After a lot of negotiating, what started off as a proposal for a medical/dental outpatient clinic (with a proposed operating budget of $2,000,000 per year) became whittled down to a dental clinic that started with only a $350,000 annual operating budget. The general consensus among the detractors of the project was that the Underwood and Lee clinic would be lucky to survive more than two years and that surely no more than 300 patients would ever come to the clinic.

I am happy to report that the detractors of the original project, from all areas, have been proven wrong. The Underwood and Lee Clinic now serves over 1,000 patients from 45 counties in the state. Despite the fact that some of our patients drive 4 to 5 hours each way to access care at our clinic, we have a 97.2% patient satisfaction rate (the other 2.8% only rated their opinion of our clinic as just “average” – none ranked it as “below average” or “poor”).

The Underwood and Lee Clinic’s research program established, early on, that it was not performing redundant care. Frequently, the clinic would see patients who had been unable to access adequate care for over 10 years. Some patients arrived at the clinic with more than a dozen painful dental abscesses in their mouths – a testament to their long-standing inability to find care at any other medical or dental facility in the state.

The teaching program at the clinic has positively affected the entire community of dental providers in the state. Since inception, nearly 500 dental students and dental hygiene students have rotated through the clinic, learning how to care for our special patient population.

Word of the success of the clinic has spread around the nation. The founders of the Underwood and Lee Clinic have been asked to consult with Senator Ted Kennedy, Senator Tom Harkin, the Surgeon General of the United States, the President's Committee on People with Intellectual Disabilities, HRSA, CMS, multiple governors and other government offices, to share their expertise in shaping this unique area of healthcare policy.

The soundness of the clinic as a fiscal investment has been recognized by both public and private insurance entities. In 2003, the clinic received an award from CMS for its innovative approach to patient care, and in 2007 the clinic received the Kentucky Area Health Underwriters award. This award has been historically reserved for the most innovative physicians: Dr. Jarvik for his work on the world's first artificial heart, Drs. Kutz and Kleinert for their work on the world's first hand transplant, and C. Everett Kopp for his work as Surgeon General are some of the previous recipients. 2007 marked the first year ever that this award was given to a dentist. That dentist was Dr. Henry Hood – for his ground breaking work at the Underwood and Lee Clinic.

The feedback from patients of the clinic has been so positive that in 2008, the state approved a $10 million appropriation to help expand the clinic. This is perhaps the most amazing part of the story of the Underwood and Lee Clinic. In these tough economic times, in a political environment of extraordinary budget shortfalls, massive budget cuts, and even a major political shift from a Republican administration to a Democratic administration, the Underwood and Lee Clinic prevailed as one of the few projects worthy of capital investment in the Commonwealth of Kentucky.

By 2012, the Underwood and Lee Clinic will open the doors of its new clinic. At that time, it will have the capacity to serve over 4000 people with ND/ID, in the fields of medicine, dentistry and psychiatry / behavioral care. It will have an annual operating budget of between $4 -$5 million.

To be sure, as with any new venture, there is no guarantee of success. Creating a successful Community Resource Center requires the proper vision, funding stream, personnel, knowledge base and management. Over the past 10 years, we have learned many of these lessons through trial and error. Should your state choose to invest its resources into a similar model of care, however, I can assure you through personal experience that with the proper attention to these factors, the CRC model can be successful in your as well.

If you would like to speak with us in more detail about our experience with the Underwood and Lee Clinic we would be happy to answer any questions. Please feel free to contact us at anytime.

Sincerely,

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