April 5, 2012

New Jersey Department of Human Resources
Division of Developmental Disabilities
Task Force on the Closure of Human Developmental Centers
c/o Barbara Booth
PO Box 762
Trenton, NJ 08625

By email (4/5/12), **Barbara.Booth@dhs.state.nj.us**
By U.S. Priority Mail (4/5/12)

Re: **Written Testimony submitted by VOR for consideration by the Task Force on the Closure of State Developmental Centers**

Dear Task Force Members:

We represent VOR, a national advocacy organization for persons with intellectual and developmental disabilities (ID/DD) and their families and legal guardians. Specifically, we serve as VOR's New York State Coordinators and have a brother with profound intellectual and developmental disabilities who receives state facility-based care in Connecticut. Our professional and advocacy qualifications are attached (***see***, **Attachments A and B**).

VOR offers the Task Force a unique organizational perspective, but one that is consistent with the perspective of families. ***Choice matters***. 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 (Intermediate Care Facilities for Persons with Mental Retardation (ICFs/MR)), including New Jersey's Developmental Centers.

VOR's respect for families as experts in their loved ones care 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 [*see* **Section II: The People Being Served** *(p. 3, below*)]. They rely on their families to ensure they receive high quality care. Their families know them best and have no ulterior motives other than their well-being.

As our written testimony will explain in detail, VOR supports the expansion of desperately needed community-based options, but not at the expense of equally necessary developmental centers (ICFs/MR).

We are gravely concerned that the Task Force's charge predisposes the Task Force to identify one or more developmental center for closure. Instead, the question, consistent with the best interests of New Jersey citizens with intellectual and developmental disabilities and federal law, is ***whether*** any developmental center should close. VOR submits that the Task Force must reframe its focus or risk violating federal law and harming fragile citizens. We contend that objective consideration of the required criteria, all relating to choice and cost, will support a "no closure" Task Force Recommendation.

Per Public Law 2011, c. 143, the Task Force is required to "perform a comprehensive evaluation of all the State developmental centers and provide recommendations for the closing of developmental centers," to include criteria (in order of importance) relating to -

a. Individual and guardian choice and interdisciplinary team recommendations;

b. Community capacity;

c. Operational needs of the Department of Human Services in meeting the range of needs and preferences of all affected individuals served by the Division of Developmental Disabilities in the Department of Human Services;

d. The economic impact on the community in which the developmental center is located; and

e. The projected repair and maintenance costs of the developmental centers.

These criteria all relate to choice and cost factors, with choice appropriately weighted more heavily than any other factor (*see*, **Section III: Individual Choice is Required by State and Federal Law**, p. 4, below). Consideration of these criteria, with *Olmstead*, Medicaid, and State Guardianship laws necessarily underpinning any review, will lead the Task Force to a conclusion that preserves developmental center supports and expands community-based options by better utilizing the existing developmental center's professional supports and infrastructure.

Our detailed written testimony follows.

I. Quality and Outcomes: Lessons Learned from New York and Other States

The deinstitutionalization experiment in other states, including neighboring New York, has led to tragic outcomes. 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. The failings of New York's system of care for individuals with ID/DD are now a well-publicized lesson learned that Task Force members must heed.

As a result of an ongoing series of articles in the *New York Times* by Albany Bureau Chief Danny Hakim entitled "Used and Abused,"[i] last year the public learned in depth about the horrific crimes committed against the developmentally disabled in New York State. Until recently, the majority of these offenses have gone unreported and un-prosecuted. While Medicaid fraud[ii] was being committed by more than one unethical service provider, residents of both "community" group homes were prey to abuse, neglect and, in 1,200 of the most heinous instances, death.[iii]

Whether receiving care in a community group home or a state run residence, people with ID/DD deserves a safe environment staffed by competent caregivers who benefit from regular supervision by administrators who are accountable to government oversight – oversight which is sorely lacking in community-based settings.

Sadly, these now well-documented tragedies, in New York and beyond, are widespread. In at least 30 states and the District of Columbia, reports of ***systemic*** abuse, neglect and death have appeared in newspapers, state audits, and scholarly journal articles. (See, "Media coverage highlighting the increasing need for more effective federal and state protections in the ever-expanding community system of care for people with intellectual disabilities," VOR (rev. November 2011; http://vor.net/images/AbuseandNeglect.pdf). In New Jersey, State inspectors uncovered violations that jeopardized the health and safety of disabled people in more than half of the 86 group homes in Bergen and Passaic counties. Inspection reports reviewed by *The Bergen Record* found dozens of instances where residents were given improper medication or failed to receive prescribed treatments. The 136 reports, which covered a four-year period, also cited homes for lack of care, improper medication, employing untrained staff and failing to keep complete records ("N.J. finds dangers in group homes," *The Bergen Record* (June 23, 2002).

Congress, the U.S. Surgeon General, the General Accountability Office and CMS have also cited serious concerns regarding compromised quality in community settings. 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." (Satcher, David, "Closing the Gap: A National Blueprint to Improve the Health of Persons with Mental Retardation, Report of the Surgeon General's Conference on Health Disparities and Mental Retardation" (February 2002); See also, Disability Rights Education and Defense Fund, March 2011 ("People with disabilities experience more problems accessing health care than other groups, and these difficulties increase for those with the most significant disabilities and who are in the poorest health"; http://www.dredf.org/healthcare/index.shtml).

Lack of access to health care was one reason cited in peer-reviewed study that found risk of morality to be 72% higher among individuals who had been displaced from state ICFs/MR as compared to those who did not move.[iv]

While 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 **<u>not</u>** subject to uniform quality assurance standards (***see***, **Attachment D**). In stark contrast, community programs are subject to very little, if any, state or federal oversight. Failures (including deaths) are often not identified until tragedy occurs and headlines result.

II. The People Being Served At New Jersey's Developmental Centers Have Profound Intellectual Disabilities and Extreme Functional Needs

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 <u>neediest</u>, <u>most fragile</u> and <u>most disabled</u> members of our society. They need support in every aspect of life including walking, communicating, bathing, eating and toileting.

Nationally, 76% 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[v].

In New Jersey, 80.3% of developmental center residents have severe or profound intellectual disabilities, with nearly 60% (58.4%) having two or more additional disabling conditions such as cerebral palsy, blindness, hearing impairments, seizure disorders, psychiatric and behavioral disorders.[vi] A vast majority of residents cannot communicate "basic desires verbally" (74.3%) and a majority cannot "understand simple verbal requests" (51.7%).[vii] Many developmental center residents also need assistance walking (40.3%), transferring (59.5%), eating (67.9%), dressing (82.9%) or toileting (76.2%).[viii]

As developmental centers in New Jersey have been downsized, the level of need among remaining residents has increased dramatically. In just 2 years, the percentage of individuals in ICFs/MR who cannot communicate "basic desires verbally" rose nearly 25%, from 49.4% in 2008[ix] to 74.3% in 2010[x]. In every "functional limitation" category – walking, transferring, eating, dressing and toileting – the percentage of developmental center residents experiencing functional limitations increased dramatically, from 11.9% (walking) to 24.9% (dressing).

In New Jersey 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. The Task Force must determine ***whether*** any developmental center homes should close by first asking ***where*** current residents will receive life-sustaining services and ***at what cost***? Doesn't the fact that there are 8,000 people waiting for services – which is growing almost daily – show that community capacity is already non-existent even for individuals who by vast majority have far less extensive needs than current developmental center residents? Is New Jersey prepared to ***FUND*** small, scattered intensive care units for these fragile citizens through the State? See *Section VI* below (page 9) for a detailed discussion on the dangers of relying on faulty cost assumptions associated with closures.

III. Individual Choice is Required by State and Federal Law

VOR respectfully submits that of all the people and organizations providing testimony to the Task Force, the perspective that matters most is that of the families. As recognized by the U.S. Supreme Court:

> ". . . close relatives and guardians, both of whom likely have intimate knowledge of a mentally retarded person's abilities and experiences, have valuable insights which should be considered during the involuntary commitment process." Heller v. Doe, 509 U.S. 312 (1993) (see also, 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.")

Families have no ulterior motive – not profit, not ideology. They seek only the best care in the most appropriate care setting for their loved ones with profound cognitive disabilities.

On Monday, March 26, the Task Force heard from several family representatives, including Cindy Bartman. Ms. Bartman is VOR's New Jersey State Coordinator, President of the Association for Hunterdon Developmental Center, President of the New Jersey Coalition of Families:

> In addition to [families'] moral motivations to ensure the very best, most appropriate care for their disabled loved ones, many family members are also court-appointed legal guardians. In this capacity they, according to New Jersey's guardianship law, are "legally authorized and responsible to act on behalf of a [minor or] incapacitated adult [to assure provision for the health, safety, and welfare of the individual and to protect his or her rights]." (N.J.A.C .10:46C-1.3).
>
> Attorney Paul Prior talks about this legal obligation in his Spring 2011 article, "Personal Decision-Making and Guardianship" published by <u>People and Families</u>, a New Jersey Council on Developmental Disabilities publication. He states, "The legal standard of guardianship for an adult is the inability to govern oneself and manage one's affairs. The cornerstone of any legal discussion of guardianship is the concept of informed consent. Informed consent means that before agreeing to something major, the person must understand what is being proposed and the consequences of the proposal, both pro and con, as well as the available alternatives." (Cindy Bartman, President Association for Hunterdon Developmental Center, Testimony for the Task Force on State Developmental Center Closure, March 26, 2012).

Despite propaganda to the contrary, federal law, including the landmark <u>Olmstead</u> decision,[xi] **requires choice** and does not require that *all* people with disabilities be served in community-based settings, nor does <u>Olmstead</u> require that ICFs/MR be closed.

Rather, in its <u>Olmstead</u> 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 (<u>Olmstead v. L.C.,</u> 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." <u>Olmstead v, L.C</u>, 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)[xii]; 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.”)[xiii]

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:

> “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)[xiv]

In New Jersey, a simple survey (December 2009) was conducted to ascertain choice. The result was clear: 96% of respondents supported maintaining current ICF/MR services and we were opposed to transition to the community.

Medicaid law also requires choice. 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 New Jersey's ICF/MR residents be granted a choice between an ICF/MR and HCBS waiver alternatives.

IV. A Mandate to Close ICF(s)/MR (Developmental Centers) Contravenes Medicaid Law and Olmstead's Requirements to Adhere to Individual Habilitation Plans

New Jersey's developmental centers provide cost-effective, specialized services and care not available elsewhere for the State's most disabled citizens. Developmental Centers are federally-licensed Intermediate Care Facilities for Persons with Mental Retardation (ICFs/MR).

According to the U.S. Department of Health and Human Services' Centers for Medicare & Medicaid Services (CMS), ICFs/MR provide comprehensive and individualized health care and rehabilitation services to individuals to promote their functional status and independence to individuals whose disabilities are profound:

> "ICF/MR is available only for individuals in need of, and receiving, active treatment (AT) services. AT refers to aggressive, consistent implementation of a program of specialized and generic training, treatment and health services. AT does not include services to maintain generally independent clients who are able to function with little supervision and who do not require a continuous program of habilitation services. States may not limit access to ICF/MR service, or make it subject to waiting lists, as they may for HCBS. . ." (CMS, "Intermediate Care Facilities for Persons with Mental Retardation (ICF/MR)"; http://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Delivery-Systems/Institutional-Care/Intermediate-Care-Facilities-for-Individuals-with-Mental-Retardation-ICFMR.html)

To be eligible for ICF/MR services, residents must be in need of, and receive, "active treatment." [42 U.S.C. §440(b)]. Active treatment refers to aggressive, consistent implementation of a program of specialized and generic training, treatment and health services, and does not include services to maintain generally independent clients who are able to function with little supervision and no active treatment [42 U.S.C. §440(a)(1) and (2)].

The Active Treatment condition of participation includes a requirement that each ICF/MR resident receive an "individual program plan" (IPP) assessment at least annually (often more) developed by an "interdisciplinary team that represents the professionals, disciplines or service areas that are relevant to – (i) identify the client's needs . . .(ii) Designing programs that meet the client's needs." [42 U.S.C. §440(c)(1)(i) and (ii)]. Furthermore, this regulation requires participation by the client, and where appropriate, his or her legal guardian. [42 U.S.C. §42 U.S.C. §440(c)(2)]. In New Jersey the IPP is called an Individual Habilitation Plan (IHP).

To assess compliance with federal conditions of participation relating to resident IHP's, state and federal surveyors are instructed to watch for plans "from individual to individual that have a predictable sameness about them" and when "prepackage programs" are used, surveyors are required to consider whether "needed individual adaptations" are made and tailored to individual need. [Guidance to Surveyors, §483(c)(1)(Probes)]. Likewise, the U.S. Supreme Court's *Olmstead* decision requires deference to the opinion of "treating professionals" who have participated the person's comprehensive functional assessment or creation of the person's individual program plan in the developmental center (ICF/MR).

Federal ICF/MR regulations relating to discharge recognize that displacing ICF/MR residents will lead to harm if discharge is not appropriate based on an individual's support requirements as determined in IPP assessments or if the individual cannot be provided with adequate services upon discharge. (42 C.F.R §483.440(b)(4); *see also* Olmstead v. L.C., 527 U.S. 581, 602 (1999)(holding that individuals have a federally protected right to receive recommendations from treating professionals as to whether community placement is appropriate and to oppose that transfer). If discharge or transfer from the facility becomes a possibility for the person, ICF/MR regulations require that the facility: (a) provide a reasonable time to prepare the client and his or her parents or guardian for the transfer or discharge, (b) develop a final summary of the individual's program plan and (c) provide a post-discharge plan of care. [42 C.F.R. §483.440(b)(4)]

Therefore, any directive by Public Law 2011, c. 143 for the Task Force to close one or more developmental centers without regard to Individual Program Plans or without consultation with the residents treating professionals would seem to directly contravene ICF/MR federal regulations and Olmstead. Task Force members do not have professional knowledge of the person's treatment needs and do not even know each person. Regardless, it is the person's *treating professionals* that the *Olmstead* Decision and Medicaid law empowered to make judgments about the appropriateness of services, including community-based services.

The imposition of a Task Force directive to close a center and discharge individuals without adequate individual planning directly contravenes and precludes the appropriate professional judgment of the treating professionals as well as the normal development and implementation of the Individual Program Plan as required by federal ICF/MR guidelines. Consequently, individuals are separated from life-sustaining supports and active treatment services only available at ICFs/MR. Tragedy, as discussed above, is predictable.

V. New Jersey Policy and Past Practices Artificially Reduce Census and Dramatically Misrepresent Choice, Contrary to Medicaid Law and Olmstead

a. Eligibility for Community Placement Dramatically Overstated

Current census numbers at New Jersey Developmental Centers and historic downsizing do not reflect demand or need.

On January 12, 2001, the Division of Developmental Disabilities (DDD) issued a memo to all Habilitation Plan Coordinators (HPCs) directing that all interdisciplinary teams determine every resident of ICFs/MR eligible for community placement "unless they represent a serious danger to others." (*emphasis* in original). As a result of this directive, since 2001 DDD has ***claimed*** that 2,400 people "wanted to leave the Developmental Centers."

More recently, compounding this myth, DDD has changed the IHP template to use person-first language, so it appears that in every case the individual spoke the words contained in the IHP. Thus, nearly ***every*** IHP in New Jersey states that the client is eligible for community placement (because relatively few are found to fit the restrictive definition of "serious danger to others,"); ***and*** it appears that the client personally expressed this preference.

The faulty IHP findings for ICF/MR residents in New Jersey are due to boilerplate application of the IHP process, contrary to federal ICF/MR regulations. On its face, New Jersey's IHP approach results in IHPs suffering from the very "predictable sameness" that CMS has recognized to be the antithesis of "individualized" planning. The negative consequences of this broad brush approach are compounded by the participation of New Jersey's Bureau of Guardianship Services (BGS), which serves as legal guardian for ICF/MR residents who otherwise lack representation. BGS, however, is an agent of the state and does not act as an independent representative of the residents it represents. Without exception, BGS follows the state directive with regard to eligibility for community placement.

These bogus numbers are not without consequence. In response to an alleged "2,457 individuals who have a recommendation for Community Placement in their IHP," New Jersey implemented its "Path to Progress," which included contracting with agencies to assist in moving people from developmental centers. In addition, the New Jersey protection and advocacy agency filed a lawsuit aimed at transitioning people from developmental centers due to the myth of thousands being inappropriately placed.

Family advocates have worked very hard to dispute the statistics relating to the number of individuals allegedly eligible for community placement. In 2006, members of the Association for Hunterdon Developmental Center along with their families and friends signed a petition regarding choice. The mailing only went to families of Hunterdon Center and 2,300 signatures were collected asking the legislature in New Jersey to investigate the forced removal of clients from Centers. As noted above, in 2009, all but one New Jersey Developmental Center family association participated in a survey of all families and guardians of residents of participating centers. A remarkable 96% of respondents (1,374) preferred continued ICF/MR services over community services. The Bureau of Guardian Services declined to participate in the survey.

b. Demand for Developmental Centers Unknown

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. When individuals are admitted in these limited situations, the New Jersey Olmstead Initiative requires that the Developmental Center recommend 3 residents for discharge to ensure the center's census does not increase and in fact decreases:

> "Additionally, a new initiative has been instituted regarding emergency admissions. When individuals require emergency admission to developmental centers and it is unlikely that they will return to their placements, developmental centers will submit the names of three individuals who meet a similar profile to the agency for consideration to fill existing vacancies." [New Jersey Department of Human Services (DHS), Division of Developmental Disabilities (DDD), "Addendum to the Olmstead Path to Progress: Blueprint for the June 30, 2013 Closure of Vineland Developmental Center," (May 2011)]

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. The emergency placement initiative – requiring 3 people to move out for every one emergency placement – is especially objectionable given that nearly all residents and their families overwhelmingly supported continued developmental center supports and objected to transition from the center. The survey (December 2009) asked families of developmental center (ICF/MR) residents if they were happy with the current placement of their loved ones or would they prefer community-based care instead. The results were overwhelmingly (96%) in support of continued ICFs/MR placement. 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)?

The lack of community capacity is also well documented. Proposals to close Vineland Developmental Center were accompanied by state claims that there was not enough funding to build new homes for the 8,000 people waiting for community-based services. 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.

VI. Developmental Centers Provide Cost Effective Care. Task Force Cautioned To Question Faulty Cost Savings Assumptions Associated With Closure(s)

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."[xv] (***see*, Attachment C**)

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 New Jersey, 80% 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.

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[[xvi]].
>
> “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,** http://www.sj-r.com/top-stories/x26164536/Closing-JDC-would-cost-Morgan-County-47-million-report-finds).

VII. 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. New Jersey is no exception: 8,000 individuals await services with more people added to the list every day. 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 New Jersey's existing Developmental Centers, while also allowing admissions to New Jersey's 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 New Jersey communities **(*see,* Attachment G)**.

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.[xvii] 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 G).**

New Jersey lawmakers are encouraged to speak directly with Dr. Holder.

VIII. Conclusion

Thank you for this opportunity to present our testimony. While community expansion is desperately needed, it must not take place on the backs of the fragile residents receiving life-sustaining supports in New Jersey developmental centers.

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. ICFs/MR have a critical role to play in serving as community resource centers that offer cost-effective services to the broader ID/DD community, including residents of neighboring local and regional group homes. ICFs/MR can provide preventative medical, dental, ocular services and socialization opportunities by enlisting the expertise of their already existing healthcare professional staff who are familiar with and able to successfully meet the needs of this arguably unique and often demanding population.

Thank you for your thoughtful consideration and your compassionate leadership. Please support a full spectrum of services and supports, including New Jersey's Developmental Centers, to meet the diverse needs of all New Jersey 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,

/s/ Hugh Dwyer

/s/ Cristy Dwyer

Hugh and Cristy Dwyer
VOR New York State Coordinators
72 Carmine Street - Rear Duplex
New York, NY 10014
(212) 929-4197 home
646) 387-3938 Cristy's cell
(646) 387-2267 Hugh's cell
myomax@earthlink.net

cc:

Assemblywoman Sheila Oliver, Assembly Speaker, AswOliver@njleg.org
Senator Stephen Sweeney, Senate President, SenSweeney@njleg.org
ASW Valerie V. Huttle, Chair of the Human Services Committee, AswVainieriHuttle@njleg.org
Senator Joseph Vitale, Chair of the Human Services Committee, SenVitale@njleg.org
Senator Loretta Weinberg, Majority Leader, SenWeinberg@njleg.org
Sybil Finken, VOR co-President; VOR Iowa State Coordinator
Ann Knighton, VOR co-President; VOR Georgia State Coordinator
VOR Board of Directors
Julie Huso, VOR Executive Director
Cindy Bartman, President, Association for Hunterdon Developmental Center; President, New Jersey Coalition for Families; VOR New Jersey State Coordinator
Geoffrey Dubrowsky, VOR Board Member (New Jersey)

ATTACHMENT A

CRISTY DWYER

72 CARMINE STREET - REAR DUPLEX - NEW YORK, NY 10014
(646) 387-3938 - (212) 929-4197
CRISTYSMYROMAX@EARTHLINK.NET
http://cristydwyer.com/

- **Empirical and theoretical knowledge of current public health and social policy issues**
- **Deep background in behavioral healthcare and advocacy services for the underserved**
- **Proven abilities to work independently or collaborate as a member of a multidisciplinary team within NYC government, private and non-profit sectors**
- **Solid organizational talents with the experience and expertise to manage multiple projects simultaneously, meet short deadlines in a fast paced environment, and work creatively with a diverse group of stakeholders**

EXPERIENCE

6/2009 to present
New York State Coordinator - VOR
Washington, DC Initiative Conference Volunteer & Legislative Advocate

- Serve as VOR's New York State Coordinator and advocacy liaison to help ensure the civil rights of those most affected by profound and severe intellectual disabilities are protected and given a voice in Congress
- Successfully lobbied New York Congressional Delegation on Capitol Hill in June of 2009, 2010 & 2011 to help garner bi-partisan co-sponsors for **H.R. 2032** (formerly H.R. 1255) – a bill authored by Rep. Barney Frank and Rep. Debbie Wasserman-Schultz designed to ensure parents and guardians of profoundly and severely disabled individuals remain informed and given the right opt out of federally funded class action lawsuits that determine where their loved ones will reside

2/2007 to present
Faculty Course Designer and Educator
Alcoholism Council of New York (ACNY) - New York, NY

- Research and design evidenced based course content for the Credentialed Alcoholism and Substance Abuse Counselor (CASAC) training program for licensure issued by the New York State Office of Alcohol and Substance Abuse Services (OASAS)
- Instruct and train beginning students and practicing professionals in the field of alcohol and drug abuse treatment and counseling services

11/2008 to 5/2009
Community Affairs & Constituent Services – Academic Internship
Office of Manhattan Borough President Scott M. Stringer - New York, NY

- Researched and drafted *A Guide to Accessing Healthcare for the Uninsured in New York City* – a handbook outlining available healthcare services for targeted populations in New York City
- Provided administrative support throughout the 2009 Community Board member appointment process including conducting candidate interviews and contributing to evaluations of applicants
- Assisted constituents with questions and concerns through telephone communications, drafting correspondence and conducting research to facilitate problem resolution

1999 to 2006
Clinical Director Rehabilitation Services
Cornerstone of Medical Arts Center Hospital - New York, NY

- Managed and designed program for a 35 bed in-patient substance abuse rehabilitation unit

- Coordinated medical and clinical team, provided clinical supervision and annual evaluations for 13 staff; managed CASAC internship program
- Facilitated direct admissions from citywide referral sources including family treatment courts, hospitals and other treatment facilities
- Worked as liaison with citywide employee assistance programs, judicial system & health management organizations
- Implemented performance improvement programs in compliance with government licensing, accreditation and certification entities such as OASAS, The Joint Commission, and the Commission on Accreditation of Rehabilitation Facilities
- Hospital wide Administrator on Duty/On Call responsibilities provided night and weekend coverage consultations to all hospital staff during monthly rotation schedule

EDUCATION

Master of Arts in Social Policy – (All but thesis) Graduation expected fall 2012 (Current **GPA 4.O**)
State University New York Empire State College, School for Graduate Studies, New York, NY
2011 SUNY Graduate Diversity Fellowship Program recipient
Awarded Empire State College Foundation Scholarship for Fall 2010 and Spring 2011 terms
2011 Student Advisory Board Member, SUNY Empire State College, School for Graduate Studies

Bachelor of Science, Public Health Policy - GPA 3.97
November 2009 SUNY Empire State College, Saratoga Springs, NY
Associate in Science, Interdisciplinary Studies - GPA 4.00
February 2008 SUNY Empire State College, Saratoga Springs, NY

Honors: 2012 SUNY School for Graduate Studies Outstanding Research Award; 2012 SUNY Dean's Medal recipient; 2010 SUNY Chancellor's Award for Student Excellence recipient; Invited by SUNY Empire State College to speak at the Center for Distance Learning Graduation ceremony in June 2008

Publications: On Progress and Privacy: Protecting Patient Confidentiality in Electronic Medical Records, (http://docs.google.com/Doc?id=dcrzcrb2_0f22w2khn) May 2009, Prof. Nicola Martinez, Ph.D. blogspot; Queen Lili'uokalani's Imprisonment Quilt: Indomitable Spirits in Protest Cloth. *Femspec Interdisciplinary Journal.* Volume 9, Issue 2. 2008

COMMUNITY INVOLVEMENT

April 2012 – April 2014
Borough of Manhattan Community Board 2 - New York, NY

- Board Member appointed to serve by Manhattan Borough President Scott M. Stringer

2002 to present
Carmine Street Block Association - New York, NY

- Executive Committee Member & Event Coordinator

CERTIFICATIONS

1997 – present
Credentialed Alcoholism and Substance Abuse Counselor (CASAC)
New York State Office of Alcoholism and Substance Abuse Services, Albany, NY

ATTACHMENT B

HUGH E. DWYER

72 CARMINE STREET - REAR DUPLEX - NEW YORK, NY 10014
(646) 387-2267 - (212) 929-4197
MYROMAX@EARTHLINK.NET

EXPERIENCE

7/2004 to present
Special Applied Intelligence, Long Island City, NY – Financial Officer

1980 to present
Independent Audio Engineer/Producer, New York, NY

6/2009 to present
New York State Coordinator - VOR
Washington, DC Initiative Conference Volunteer & Legislative Advocate

- Serve as VOR's New York State Coordinator and advocacy liaison to help ensure the civil rights of those most affected by profound and severe intellectual disabilities are protected and given a voice in Congress
- Successfully lobbied New York Congressional Delegation on Capitol Hill in June of 2009, 2010 & 2011 to help garner bi-partisan co-sponsors for **H.R. 2032** (formerly H.R. 1255) – a bill authored by Rep. Barney Frank and Rep. Debbie Wasserman-Schultz designed to ensure parents and guardians of profoundly and severely disabled individuals remain informed and given the right opt out of federally funded class action lawsuits that determine where their loved ones will reside

EDUCATION

Bachelor of Science Business 2006
State University of New York, Empire State College, Saratoga Springs, NY

COMMUNITY INVOLVEMENT

2005 to present
Southbury Training School, Home and School Association, Southbury, CT - Member

2002 to present
Carmine Street Block Association, New York, NY, Executive Committee Member

2006 to 2008
The Imagine Project, Org., Brooklyn, NY - Audio Engineer/Producer

ATTACHMENT C

(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 D

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 E
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/CertificationandComplianc/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 F

October 12, 2011

Dear Chairpersons Van Drew and Huttle and Members of the Review Panel:

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 New Jersey 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 New Jersey 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,

Matthew Holder, MD, MBA
CEO, Underwood and Lee Clinic
Executive Director, American Academy of Development Medicine and Dentistry
www.underwoodandlee.com
mattholder@aadmd.org
502-368-2348 (w)
502-368-2340 (f)

---

[i] Danny Hakim, "Used and Abused," article series in the *New York Times* examining the treatment of the developmentally disabled in New York State and how money is spent on their care 2010- 2011. http://www.nytimes.com/interactive/nyregion/abused-and-used-series-page.html

[ii] Financial exploitation was also 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."

[iii] Danny Hakim, "In State Care, 1,200 Deaths and Few Answers," *New York Times*, November 5, 2011. http://www.nytimes.com/2011/11/06/nyregion/at-state-homes-simple-tasks-and-fatal-results.html?_r=3

[iv] Strauss, D., et al., "Mortality of adults with developmental disabilities living in California institutions and community care, 1985-1994," Mental Retardation (1998); for a link to this and similar studies with consistent conclusions, see, http://www.lifeexpectancy.com/articles.shtml.

[v] "Residential Services for Persons with Developmental Disabilities: Status and Trends Through 2010,"Research and Training Center on Community Living Institute on Community Integration/UCEDD, College of Education and Human Development University of Minnesota (2012) (http://rtc.umn.edu/docs/risp2010.pdf)

[vi] Id.

[vii] Id.

[viii] Id.

[ix] Id.

[x] "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)

[xi] 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.

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

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

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

[xv] 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 C*).

[xvi] "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.

[xvii] 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.