VOR
1963-2013
30th ANNIVERSARY
Speaking out for people with intellectual & developmental disabilities

Toll free
877-399-4867

www.vor.net

Executive Director
Julie M. Huso
836 S. Arlington Heights Rd, #351
Elk Grove Village, IL 60007
605-370-4652 Voice
605-271-0445 Fax
Jhuso@vor.net

Dir. of Govt. Relations & Advocacy
Tamie Hopp
PO Box 1208
Rapid City, SD 57709
605-399-1624 Voice
605-399-1631 Fax
Thopp@vor.net

Washington, D.C.
Larry Innis
529 Bay Dale Court
Arnold, MD 21012-2312
410-757-1867 Voice/Fax
LarryInnis@aol.com

VOR Comments to Federal Commission on Long-Term Care

Abstract

July 31, 2013

VOR is a national organization advocating for high quality care and human rights for all people with intellectual and developmental disabilities. VOR represents families of individuals with intellectual and developmental disabilities (I/DD), many of whom experience severe and profound developmental disabilities, have multiple physical disabilities, and are medically fragile or experience dangerous behaviors.

VOR strongly supports long-term services and supports (LTSS) that are responsive to the needs of all *individuals* with disabilities, recognizing that “equitable” does not mean identical when dealing with human needs. Too often the quest for “rebalancing” the service system – to shift “institutional” funding to community-based supports – neglects person-centered supports in an unreasonable, and potentially dangerous, quest for “sameness.” The human condition is not that convenient. The cost to care for individuals must necessarily vary and be responsive to varying needs. VOR urges the Commission to consider the unique long term care needs of the disabled population and be mindful of the fact that “one size does not fit all.”

The following summarizes our comments, concerns and recommendations:

1. From a fiscal perspective, believable cost comparisons reinforce common sense.

The Commission is urged to scrutinize fantastical comparisons that suggest community care costs are only $26,000/year as compared to $220,000/year per individual in facility-based homes. Congregate care facilities mitigate risk to the client while providing efficiencies of cost not found in informal settings (e.g., group homes).

2. Consider an *individual’s* needs – often life-sustaining needs – as the foundation of successful planning.

3. The service system must be responsive to an array of human needs, and consideration for future needs. Like a hospital, the LTSS system must provide for all levels of need now and in the future. Demographic and policy trends, including the impending wave of aging baby boomers and the numbers of elderly caregivers, will only further stress the service system.

4. Don't repeat past failures: VOR strongly believes that aggressive, forced deinstitutionalization (without regard to individual need or preference) and an over-reliance on informal caregivers (e.g., elderly parents) has resulted in widespread, documented **human tragedies** (*see*, Widespread Abuse, Neglect and Death in Small Settings Serving People with Intellectual Disabilities, 2013) and a **waiting list** that has doubled to 268,000 since 2007. As long as closure advocates perpetuate the myth that forced deinstitutionalization, without regard to individual need or preference, will save money, policymakers will persist and the suffering will continue. This Commission must help with recommendations that are fiscally realistic and support an array of LTSS to meet all levels of need.

5. Personal choices and needs are the governing factors: For families living with a severely disabled family member, a utopian vision of a world where everyone, regardless of the nature or severity of his or her disability, lives a fully integrated, independent life in "the community" (whatever that means) and engages in competitive employment makes as much sense as a vision of a world where severe disabilities don't exist at all.

We need realistic solutions, not over-simplified notions that only serve to limit the range of choices. In addition to the current array of choices, including institutional care, creative family and community-based projects that provide specialized services and residential options to people with I/DD should be encouraged, not prevented from getting the assistance they need to succeed.

Thank you for your consideration. Our detailed comments are attached.

30th 1983-2013 ANNIVERSARY
VOR
Speaking out for people with intellectual & developmental disabilities

Toll free
877-399-4867

www.vor.net

Executive Director
Julie M. Huso
836 S. Arlington Heights Rd, #351
Elk Grove Village, IL 60007
605-370-4652 Voice
605-271-0445 Fax
Jhuso@vor.net

Dir. of Govt. Relations & Advocacy
Tamie Hopp
PO Box 1208
Rapid City, SD 57709
605-399-1624 Voice
605-399-1631 Fax
Thopp@vor.net

Washington, D.C.
Larry Innis
529 Bay Dale Court
Arnold, MD 21012-2312
410-757-1867 Voice/Fax
LarryInnis@aol.com

VOR Comments to Federal Commission on Long-Term Care
Detailed Attachment
July 31, 2013

Bruce A. Chernof, MD
Chair, Federal Commission on Long-Term Care

Mark Warshawsky, Ph.D.
Vice-Chair, Federal Commission on Long-Term Care

Commissioners: Dr. Javaid Anwar, Judy Brachman, Laphonza Butler, Henry Claypool, Judy Feder, Stephen Guillard, Chris Jacobs, Neil Pruitt, Jr., Carol Raphael, MPA, M.Ed, Judy Stein, Grace-Marie Turner, and George Vradenburg

Submitted by email: comments@ltccommission.senate.gov

Dear Dr. Chernof, Vice-Chair Warshawsky, and Commissioners:

I represent VOR, a national organization advocating for high quality care and human rights for all people with intellectual and developmental disabilities. We represent families of individuals with intellectual and developmental disabilities (I/DD), many of whom experience severe and profound developmental disabilities, have multiple physical disabilities, and are medically fragile or experience dangerous behaviors. They require total care provided through Medicaid in long-term care community and facility homes.

On their behalf, we appreciate this opportunity to offer our perspective with regard to the need for long-term services and supports (LTSS) that are responsive to the needs of all people with disabilities, recognizing that “equitable” does not mean identical when dealing with human needs. Below, VOR addresses important issues that directly relate to the charter of the Federal Commission on Long-Term.

Too often the quest for “rebalancing” the service system – to shift “institutional” funding to community-based supports – neglects person-centered supports in an unreasonable, and potentially dangerous, quest for “sameness.” The human condition is not that convenient. The cost to care for individuals must necessarily vary and be responsive to varying needs.

We appreciate the hard work of this Commission and the herculean challenge it has ahead in developing LTSS recommendations that are responsive to the needs of many constituencies while keeping the reality of fiscal constraints in mind. To that end, VOR will focus its comments on fiscal perspectives: LTSS Cost Comparisons (and the human cost of underestimating costs of care) and the myth of a Medicaid institutional bias. Both discussions support the expansion of Medicaid community LTSS and, importantly, the virtues of true person-centered planning.

LTSS Cost Comparisons

The Commission is urged to scrutinize fantastical comparisons that suggest community care costs are only $26,000/year as compared to $220,000/year per individual in facility-based homes (*see*, Testimony of David Braddock, PhD., July 17, 2013). These *average* cost comparisons are poor baselines for any realistic person-centered planning. Expectations of automatic savings, based on faulty cost comparisons has and will lead to even longer wait lists and tragic outcomes (*see*, Widespread Abuse, Neglect and Death in Small Settings Serving People with Intellectual Disabilities, 2013).

By analogy, consider the cost of care of intensive care unit (ICU) patients. The cost to provide treatment for ICU patients in their own home would skyrocket if they were provided adequate treatment. The hospital, now situated on a campus (like ICFs/IID) would lose all benefit of economies of scale inherent in triaged care in one location, and instead have to bear higher costs across scattered home settings in a community. Cost savings would only be realized if treatment was compromised – a dangerous proposition for any ICU patient. VOR strongly believes that forced deinstitutionalization, without regard to individual need or preference, supported by community-only advocates and pursued by some policymakers as a cost savings strategy, is akin to removing the most medically fragile and disabled individuals from their "ICUs" to less specialized, under-funded settings, resulting in predictable tragedies:

> "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)).

If the forces whose goal is to close specialized facilities for persons with I/DD were today in charge of our medical hospitals they would turn the lights out in all intensive care units. These same forces seem to support blindly transitioning individuals with I/DD from ICFs/IID without concern for probable reductions in service and supports and with no guarantee for improvement in condition. To the contrary, isolation, abuse, neglect or even death is often the outcome.

We urge the Commission to undertake a true accounting of costs that avoids common cost comparison myths and ensures that “apples are being compared to apples:”

- **Are all costs accounted for?** Does the cost of care in a community setting (e.g., $26,000) include equivalent costs such as housing, acute and preventative medical care, dental care, habilitative and active treatment, other specialized supports, transportation, day programming, and 24/7 care? Most community figures neglect most if not all of these “line items.”

- **Do cost comparisons take into account the differences in wages for direct care workers – a difference which will relate to the tenure and qualifications of staff?** In some community settings, wages are so low that turnover in a year is as great as 200%. Is that cost savings worth the risk? In contrast, ICF/IID enjoy relatively long tenures and receive ongoing training in medication dispensing, therapies, positioning, active treatment, infection control, nursing, injury and fall prevention, basic care needs (bathing, grooming, eating, etc.), behavioral management and more.

- **Do cost comparison account for cost shifting?** When individuals are moved from ICF/IID homes 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. The projected costs for community care is understated and not a complete look at the true costs of serving the individuals, and a false claim of taxpayer savings.

- **Do cost comparisons compare individuals with similar disabilities?** Someone with high needs will cost more to care for no matter the setting.

Peer reviewed research supports the view that costs of caring for people with I/DD will be “highly variable across settings and will vary with the characteristics of those served and the resources, especially staffing, devoted to serving them.” (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.” *Id*.

In 2011, a VOR affiliate considered the needs of a single individual and determined his individualized costs if served in a community setting. At the time of the cost analysis, the individual (Brian) was 41 years old, 6’ tall, 190 lbs and healthy. Brian receives care at a state Intermediate Care Facility for Individuals with Intellectual Disabilities (ICF/IID) at the estimated cost of $220,000/year. He is being treated for obsessive/compulsive (O/C) behaviors which presently involve consuming huge amounts of fluid; interruptions of his O/C behaviors can bring violent responses. He is prone to unpredictable explosive physical aggression toward peers, staff and property. He has been expelled from community-based programs. Here is a summary of the cost comparison findings:

Scenario #1: A one-person community-based home with one-on-one staff: $183,016 Even in this "best case scenario," guardians and many professionals in the field would judge these services to be inadequate and dangerous. Isolation, unsafe staffing levels (1:1, no back up), 911 calls, behavior intervention and psychotropic medication administration by low-wage staff, and greatly reduced professional support (as compared to the state ICF/IID) remain problems.

Scenario #2: Four-person community home (assuming that Brian improved during Scenario #1): $146,701. Guardians and professionals would have the same concerns as Scenario #1. Additionally, the assumption that Brian would improve under Scenario #1 (rather than deteriorate or place other housemates at risk, which is more likely), is not realistic because Brian depends on a high level of structure and his behaviors deteriorate with less.

Scenario #3: Professional and staff supports at community home minimally comparable to state ICF/IID supports: $270,000. Even at this cost, some of the same concerns persist, namely, isolation, lack of structure, and high risk of 911 police intervention.

(*Source*: Illinois League of Advocates, October 17, 2011;
http://www.vor.net/images/ILADDCostComparson.pdf)

While very challenging, Brian is not the most challenging among his peers at his ICF/IID; he cannot be dismissed as a uniquely expensive case. For example, he does not present severe medical conditions, seizure activities, sexual aggression, or (at this time) life-threatening pica (swallowing inedible objects).

The Myth of a Medicaid Institutional Bias

The allegation of a Medicaid "institutional bias" – that Medicaid is unfairly geared toward institutional care – for people with I/DD is not true. It is based on two false premises: (1) that all institutional services are mandatory and all home and community-based services (HCBS) are optional, and (2) that more dollars are spent on institutional services than on HCBS services.

First, all Medicaid programs for people with MR/DD are optional, whether provided through Intermediate Care Facilities for Individuals with Intellectual Disabilities (ICFs/IID) or the HCBS program.

Second, according to United Cerebral Palsy, far more Medicaid dollars are spent on HCBS than on ICFs/IID services. In the context of "rebalancing," 38 states serve at least 80% of all individuals with I/DD in the community, and 80% of all resources spent on those with I/DD are for community support; and another 5 states come "very close." This is up from only 14 states in 2007.

A note about Olmstead

Although often cited in support of deinstitutionalization, regardless of individual need or preference, the U.S Supreme Court decision of Olmstead v. L.C., 119 S. Ct. 2176, 2187 (1999) does ***not*** support the view that congregate settings are automatically discriminatory against people with disabilities and does not, even remotely, support forced deinstitutionalization when not warranted by individual choice or need.

Olmstead supports individual choice. Justice Ginsburg was very clear:

> "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.**" 119 S. Ct. at 2187 (**emphasis added**).

Stated another way:

> "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]

Recommendations

- We urge the Commission to undertake a true accounting of service setting costs that avoids common cost comparison myths and ensures that "apples are being compared to apples."

- We urge the Commission to consider costs associated with emergency room and hospitalization usage by community residents versus ICF/IID residents. We contend that good, safe care results in fewer medical problems and hospitalizations, and less costs.

- We support the National Council on Disability's (NCD's) recommendation to, "Improve the supply, retention, and performance of direct support workers to meet increasing demand. Funding should be authorized for collaborative demonstration projects between the U.S. Departments of Labor and Health and Human Services that promote collaboration between community colleges and disability-related organizations to develop a high-quality set of competencies to be taught in a new support worker certificate program that expands supplies of quality workers to meet market demand in home- and community-based settings."

- We urge the Commission to have the courage to look critically at the human and fiscal impact of forced deinstitutionalization, without regard to individual need or preference. We recognize and strongly support the need for expanded high quality community-based support option, but do not feel this can be accomplished by closing specialized settings. Thus, we strongly object to forced deinstitutionalization based ***not*** on individual choice or need, but ideology. There is no question that deinstitutionalization failed the mentally ill. There are similar and growing documented failures of the I/DD deinstitutionalization experiment.

- To expand LTSS community-based option, the Commission is urged to embrace a broad view of "community" and recommend Medicaid funding for innovative settings. A proposed federal rule, if adopted, will define "community" so narrowly that innovative settings that now survive due to Medicaid funding, such as planned communities for people with autism, will lose funding.

Conclusion

1. **From a fiscal perspective, believable cost comparisons reinforce common sense.** That is to say, <u>congregate care facilities mitigate risk to the client</u> while <u>providing efficiencies of cost not found in informal settings (e.g., group homes).</u>

2. **We must consider an individual's needs – often life-sustaining needs – as the foundation of successful planning.** This will prevent falling for the short-sighted mantra of forced deinstitutionalization at any cost, for all levels of disability, without regard to individual need or preference. Federally-licensed, specialized facilities are not the medieval "institution" portrayed by supporters of community based care for every individual – a position which harms those whose needs are the greatest.

3. **The service system must be responsive to an array of human needs, and consideration for future needs.** Like a hospital, the LTSS system must provide for all levels of need now and in the future. Demographic and policy trends will only further stress the service system. As noted by the NCD (2013), the "impending wave of aging baby boomers, increasing life expectancy, and rising disability rates in people under 65 will significantly increase the demand for LTSS in the coming decades." In addition, the number of aging caregivers of middle aged disabled children has risen to crisis proportions (*see*, Braddock (2006) (716,000 adults with developmental disabilities were living with caregivers over the age of 60 in the United States).

4. **Don't repeat past failures:**

    a. **Human tragedies:** VOR strongly believes that forced deinstitutionalization, without regard to individual need or preference, supported by community-only advocates and pursued by some policymakers as a cost savings strategy, is akin to removing the most medically fragile and disabled individuals from their "ICUs" to less specialized, under-funded settings, resulting in predictable tragedies (*see*, Widespread Abuse, Neglect and Death in Small Settings Serving People with Intellectual Disabilities, 2013).

b. **Waiting lists:** VOR contends that certain LTSS policy trends have only exacerbated current crises. The waiting list has doubled to 268,000 since 2007 (Case for Inclusion, UCP) at the same time efforts to decentralize and de-specialize the service system have been pursued with growing intensity.

c. **Increased reliance on informal caregivers**

We believe that increased reliance on informal caregivers, such as families, has also led to growing waiting lists as individuals transitioned from specialized settings are served first, albeit often inadequately. Emergency rooms have become the "primary care physician" for many high needs individuals with I/DD due to a lack of health care providers and attention to preventative care (*see* e.g., Lunsky Y., et al., "Emergency department visits and use of outpatient physician services by adults with developmental disability and psychiatric disorder," Can J Psychiatry. 2012 Oct; 57(10):601-7)("People with more severe impairments had the greatest likelihood of ER visits, despite access to outpatient services, suggesting that outpatient care (primary and psychiatric), as currently delivered, may not be adequate to meet their complex needs"). Consider this example from a VOR member:

> After my son was in intensive care for two weeks in 2009, I was struck by the difference between what Medicaid spends on hospitalization and the relatively small amounts spent on his school program and group home placement for an entire year. The cost of hospitalization according to statements we received from the hospital was over $150,000 for 3 weeks, and I estimated that the cost of his group home placement plus school program was something like $140,000 for all of 2009.

5. **Personal choices and needs are the governing factors:** For families living with a severely disabled family member, a utopian vision of a world where everyone, regardless of the nature or severity of his or her disability, lives a fully integrated, independent life in "the community" (whatever that means) and engages in competitive employment makes as much sense as a vision of a world where severe disabilities don't exist at all.

We need realistic solutions, not over-simplified notions that only serve to limit the range of choices. In addition to the current array of choices, including institutional care, creative family and community-based projects that provide specialized services and residential options to people with I/DD should be encouraged, not prevented from getting the assistance they need to succeed.

If you have any questions, please contact Tamie Hopp, VOR's Director of Government Relations & Advocacy, at 605-399-1624 or thopp@vor.net.

Thank you for your consideration.

Sincerely,

Ann S Knighton

Ann S. Knighton
President