

December 13, 2012

The Honorable Fred Upton, Chair
The Honorable Henry Waxman, Ranking Member
The Honorable Joe Pitts, Chair, Health Subcommittee
U.S. House of Representatives
House Energy and Commerce Committee
Washington, D.C. 20515

Dear Chairman Upton, Ranking Member Waxman, and Subcommittee Chairman Pitts:

I am writing on behalf of VOR, a national nonprofit organization advocating for high quality care and human rights for all people with intellectual and developmental disabilities (I/DD).

Above all else, I am father.

In my volunteer capacity with VOR, I represent thousands of mothers, fathers, sisters and brothers of citizens with profound I/DD who are receiving high quality, life-sustaining care in licensed facility homes ("ICFs/MR").

Recently, the National Council on Disability (NCD) released "Deinstitutionalization: Unfinished Business," an offensive 300 page policy document and "how to" toolkit dedicated to closing our loved ones' homes. In NCD's own words, the facts about how much deinstitutionalization is costing in human and financial terms should be ignored. Build your case "with faces, not facts," advises NCD (NCD's Deinstitutionalization Toolkit, Strategy in Detail, Part 2).

Remarkably, however, the faces that should matter most - **affected residents and their families** - **were NOT consulted** in the preparation or publication of this tome. Yet, if NCD's "call to action" is carried out, these individuals will be displaced and separated from life-sustaining services due to the NCD-supported closure of their homes.

In addition, families who have spent lifetimes doing everything possible to ensure their family members receive highly compassionate and skilled care **are accused by NCD of violating their loved ones' civil rights** simply because their care is being received in a home with four or more people.

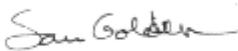
On behalf of these individuals and their families (taxpayers), VOR strongly objects to NCD's use of federal funds to produce this biased document and toolkit. (See, *NCD's Deinstitutionalization: Unfinished Business: Reckless disregard shown for the needs and choices of vulnerable persons with severe and profound disabilities* (VOR, December 2012), <http://www.vor.net/images/VORResponseNCD1212.pdf> (attached)).

NCD is just the latest federal agency to aggressively pursue the closure of facility-based homes without any regard for the input or insights of the affected residents and their families, contrary to federal law and principles. The Administration on Intellectual and Developmental Disabilities' programs including Protection and Advocacy and DD Council agencies, and the Department of Justice's Civil Rights Division are just as guilty. Millions of federal dollars are being committed by these agencies to dismantle federally-licensed homes – homes that are providing good care – simply because these federal agencies view these homes as not integrated enough.

This is not just a battle of ideology. Many individuals who have been displaced from their homes due to the efforts of these federal organizations are facing tragedies (see, [Widespread Abuse, Neglect and Death in Small Settings Serving People with Intellectual Disabilities](http://www.vor.net/images/AbuseandNeglect.pdf), <http://www.vor.net/images/AbuseandNeglect.pdf>).

Please help. Many of you are also parents. You would not stand by silently if a federal agency questioned your choices on behalf of your children. Please stand up for families of disabled citizens across the country. They need your help and your leadership.

Sincerely,



Sam Golden
Chair, VOR Government Affairs Committee
1700 E. 56th Street, #1701
Chicago, IL 60637-1370
773-288-3459 home
sgolden@uchicago.edu

For More Information

Ann Knighton
President, VOR
706-993-6329 direct

Sam Golden
Chair, Government Affairs Committee
773-288-3459 home
sgolden@uchicago.edu

Tamie Hopp
Director, Government Relations & Advocacy
605-399-1624 direct
thopp@vor.net

December 2012

VOR Response to the National Council on Disability's "Deinstitutionalization: Unfinished Business"

Reckless disregard shown for the needs and choices of vulnerable persons with severe and profound disabilities

VOR, a national organization advocating for high quality care and human rights, strongly objects, in substance and in principle, to the National Council on Disability's (NCD) newly released "*Deinstitutionalization: Unfinished Business*" policy document (110 pages) and accompanying "toolkit" (how-to manual) (201 pages).

VOR represents thousands of individuals, families and legal guardians, organizations and advocates around the country who value individual choice and recognize that true person-centered planning begins with the individual and his/her needs. One size does not fit all. An array of quality service and support options is needed to ensure that choice, based on individual need, is accommodated.

NCD used more than 300 pages to advocate for closing specialized homes – Medicaid-licensed Intermediate Care Facilities (ICFs/MR) – serving our nation's most profoundly disabled citizens. This insensitive, reckless attitude will cause these vulnerable individuals to suffer grievous harm and even death.

Unconscionably, in calling for the closure of ICF/MR homes for residents with severe and profound intellectual and developmental disabilities (I/DD), NCD alleges that these individuals are enduring *civil rights violations* at the hands of their families and guardians based solely on the size of their chosen residential setting. NCD has arbitrarily decided that any home with more than three people is an "institution," defining "institution" as a facility of four or more individuals.

Is it reasonable to expect that every three person home is somehow more humane, less costly, or will result in a higher quality of life simply based on size? Of course not, yet NCD has chosen size as the threshold question to determine whether a setting is good or bad.

It is even questionable whether NCD has the legal authority to "raise[s] the standard in a way that has not been previously tracked" by redefining what constitutes a Medicaid-certified "institution." (See, *Evolving Definition of Institution*, "*Deinstitutionalization: Unfinished Business*," ([Introduction](#))). Unquestionably, as an "independent," federally-funded organization charged with advising our federal lawmakers, NCD should **not** be taking a position that tramples on the rights of a small, but no less worthy, segment of its constituency.

NCD calls for the closure of facility-based homes of four or more people when families and legal guardians are nearly universally opposed to such closure. This is irresponsible given the widespread, well-documented tragedies associated with under-funded and ill-prepared “community” programs for individuals with profound needs. NCD has put its most fragile constituency at great risk of harm.

VOR members from across the country – families and legal guardians of individuals with profound I/DD, serious medical problems, or aggressive and assaultive behaviors, and others who simply value the right of residential choice – stand united in its opposition to NCD’s misuse of authority and federal funding. They take personal affront at the suggestion that their decisions to ensure high quality, life-sustaining care for their family member also violate their family members’ “civil rights.”

Even NCD begrudgingly concedes in its “Toolkit” that *Olmstead* **requires** individual choice and a treating professionals’ assessment that community placement is appropriate (see, *Deinstitutionalization Toolkit, Legal in Detail*). The Supreme Court recognized an ongoing role for publicly and privately-operated ICFs/MR:

“We emphasize that nothing in the ADA or its implementing regulations condones termination of institutional settings for persons unable to handle or benefit from community settings...Nor is there any federal requirement that community-based treatment be imposed on patients who do not desire it.” *Olmstead v. L.C.*, 119 S. Ct. 2176, 2187 (1999) (*majority opinion*)

“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].” *Id.* at 2189 (*plurality opinion*).

“It would be unreasonable, it would be a tragic event, then, were the Americans with Disabilities Act of 1990 (ADA) to be interpreted so that states had some incentive, for fear of litigation to drive those in need of medical care and treatment out of appropriate care and into settings with too little assistance and supervision.” *Id.* at 2191 (*Kennedy, concurring*).

The Individual and Family Voice

As noted the voices and choices of the individuals and families/legal guardians so directly impacted by NCD’s call to action are conspicuously absent from the NCD’s policy document and toolkit. Had they been asked, you would have heard stories like this:

“Was there any consideration for what is best for the residents of [the center to be closed]? **My daughter** is 44 years old and has lived in [the center’s] cottages since she was about 8 years old. She is comfortable there, is used to the hubbub, and loves the staff that cares for her. She is non-ambulatory, has a mental age of about 2-3 years old,

and has seizures. [The center] is about 53 miles from where I live. I am almost 70 years old and never dreamed that they'd pull the rug out from under my daughter's home. I don't think a group home is right for my daughter and surely hope they don't want to move her to a facility that is 3-4 hours away from me. What to do? I am scared." (E-Mail to VOR, August 2012).

Aaron is 32 years old, but has the cognitive ability of a 2 month old infant. He receives 24/7, compassionate support in care facility chosen by his parents. In their words: "Aaron was born 8 weeks premature. While he survived the birth, the lifelong effects from subarachnoid and pulmonary hemorrhages are devastating. A large portion of his brain was destroyed with the subarachnoid hemorrhage. His functional abilities are in the 2-3 month range. Seizures, respiratory insufficiency, frequent pneumonias, cortical blindness, spastic tetraplegia with ever increasing spasticity are just a few of the daily challenges for his caregivers." (Aaron's parents and VOR Wisconsin State Coordinators (2012))

Brian is 42 years old, but has the cognitive ability of a young child. He also experiences dangerous behaviors which are well-managed to keep him and other safe in a care facility chosen by his parent. In his mother's words:

"Brian was expelled from four homes in two states because of dangerous aggression. He was sent HOME where we had little children. He injured everyone in the family except the baby who was locked away from him and broke hundreds of windows (we repaired them every weekend). Finally, in 1990, a state-operated facility for people like Brian in yet another state provided him the care he needs and continues to serve him well. What apartment building would be right for Brian and which McDonald's has an application with his name on it?" (Brian's mother and VOR Illinois State Coordinator (2012))

Roger is 50 years old, but has the cognitive ability of an infant. He is medically-fragile and receives high quality, specialized supports in a care facility chosen by his mother. In her words:

"Roger suffers from brain damage due to an oxygen deficiency at birth, epilepsy with uncontrolled mixed seizures, profound swallowing problems, brittle bones, optic atrophy with myopia, incontinence, stenosis of his neck and back, peripheral neuropathy and hyper-salivation. Roger is non-verbal and completely non-ambulatory. He gets all nutrition, hydration and medication via a gastrostomy tube." (Roger's mother and VOR member from Virginia (2012))

Lauren's disabilities and needs are significant. She has severe intellectual disabilities due to corticocerebellar damage and prenatal hypoxia, fibrocystic breast disease-bilateral, a seizure disorder, degenerative osteoarthritis of the spine, spastic quadriplegia, and more. Lauren is non-communicative and non-ambulatory. Once, when

her bedroom moved from one room to another, she stopped eating.” ~ Lauren’s sister and VOR Member (2011).

“**Danny and Ian** are brothers who live in a group home in Ypsilanti, Michigan. They have severe cerebral palsy and profound intellectual disabilities. Facility care was never offered as an option, but services have been cobbled together by their parents and the local community mental health agency. Still, their parents pay for a day program and a private dentist and monitor care at the group home constantly. Many families are not able or cannot afford to fill in the gaps in services. Now that all the larger facilities for people with developmental disabilities in Michigan have closed, the advocacy groups are trying to close the only licensed facilities left – the group homes.” (Danny and Ian’s mother and VOR member from Michigan (2012))

“Within my family there are needs across the continuum. My son **Dan**, is 16 years-old, 6 feet tall and over 220 lbs. He lives at home and has severe autism. On several occasions he has attacked my wife, ripping her hair from her head and using his teeth to harm us. On recent occasions the Brick police had to be called because he was getting the best of me. They needed two officers to get him into handcuffs and took him via squad car to the local hospital ER, where they had no idea what to do. Someday soon, these attacks will leave one of us in bad shape and then and only then will the State of New Jersey realize we need out-of-home placement for him. I feel it is his right to have an array of residential options. We want these options to include developmental centers [ICFs/MR]so if he is unable to manage these outbursts, he does not harm someone. My nephew, **Ben**, is 25, has Fragile X syndrome, and lives at home with his 70 year old father. Currently he is well and involved in many programs, but cannot live alone because he is physically unable to properly toilet himself. Someday, soon however, he too will need out-of-home residential care. My niece, **Heather**, is 29, has profound autism with severe behaviors. In her teens, she put her family at serious risk of injury and destroyed their home. Since the age of 13 she has been receiving exceptional care at Hunterdon Developmental Center where skilled professionals have managed her behaviors very well, with minimal medication. She is still prone to behavioral outbursts when faced with change, but she enjoys significant independence thanks to the structured services that Hunterdon provides in her community. You see, Hunterdon is where she lives, works, has friends, and has access to medical and dental professionals prepared to deal with the severity of her disability.” (Dan’s father and Ben and Heather’s uncle and VOR Officer and Board Member, April 2012).

Conclusion

VOR members have different experiences. Some value the supports their family members with I/DD receive at home, or in smaller settings, and others value the compassionate specialized supports received in licensed facility-based homes. **All VOR families support choice based on individual and family decision-making, and seek a future for their loved ones that includes a continuum of options, including Medicaid-licensed Intermediate Care Facilities for persons with an Intellectual Disability.**

NCD has shown callous disregard for these families by publishing such an egregious affront to their collective choices and perspectives. The “*Deinstitutionalization: Unfinished Business*” policy document and the accompanying “toolkit” both accuse families and court-appointed legal guardians who support facility-based care of violating the civil rights of their family members. The document and toolkit also call on the broader advocacy community to engage in advocacy efforts and lawsuits to displace people with I/DD, who are mere strangers to those who carry the deinstitutionalization sword.

VOR calls on NCD to retract “*Deinstitutionalization: Unfinished Business*,” because “Unfinished Business” is itself unfinished.

The needs and perspectives of individuals with I/DD whose homes are the target of this document were not considered. NCD was derelict in its duty in not consulting with these individuals' families and legal guardians, the people who know them best

VOR encourages NCD to support a “systems change” designed to expand, not limit options, with a focus on expanding critically necessary “community-based” supports. VOR agrees that “community” programs are lacking in quality and capacity to serve those individuals who choose this setting and whose needs could be met with adequate supports and funding. However, a systems change that takes from one fragile population in an attempt to provide for another is not the sort of reform disability advocates should support, nor does it work. Closures opposed by the very people impacted have done nothing to address community capacity. Waiting lists continue to grow and community tragedies occur. It is time for NCD take a leadership role in acknowledging this reality and immediately work toward expanding, not eliminating, quality service options.

For More Information

Ann Knighton
President, VOR
706-993-6329 direct

Sam Golden
Chair, Government Affairs Committee
773-288-3459 home
sgolden@uchicago.edu

Tamie Hopp
Director, Government Relations & Advocacy
605-399-1624 direct
thopp@vor.net