



Speaking out for people  
with intellectual disabilities

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## VOR COMMENTS AND OBJECTIONS TO “RISING EXPECTATIONS: THE DEVELOPMENTAL DISABILITIES ACT REVISITED”

### I. Introduction

On February 15, 2011, the National Council on Disability (NCD) released a 195-page report, *Rising Expectations: The Developmental Disabilities Act Revisited*. VOR has reviewed the report, including the letter of transmittal written by Chairman Jonathan Young.

**We object to the conclusions and recommendations found in the NCD report: that the Administration on Developmental Disabilities (ADD) and the programs authorized by the Developmental Disabilities Assistance and Bill of Rights Act (DD Act) should have increased funding and also greater policymaking powers for persons with DD.**

VOR is a national organization advocating for the right of individuals with intellectual and developmental disabilities (ID/DD) and their families to choose from a full array of high quality residential and other support options. VOR members feel strongly, based on their individual experiences, that the services received be based on individual need and choice, whether received in a family home, the individual’s own home, a community setting, or in a Medicaid certified and licensed Intermediate Care Facility for persons with Mental Retardation (ICFs/MR).

### II. Summary of Objections

NCD is “an independent federal agency making recommendations to the President and Congress to enhance the quality of life for all Americans with disabilities and their families.” However, our review shows that NCD’s report is biased against congregate care settings and the report’s conclusions and recommendations cannot be considered independent and fair.

The objections of VOR to the report fall into four distinct areas. The report:

- promotes a federal agency with a questionable performance record
- provides an incomplete representation of the developmental disabilities community
- provides misleading statements regarding the intent of Congress for the DD Act
- promotes currently popular but misguided and harmful ideological policies

### III. Detailed Objections

#### A. Promotes a Federal Agency With a Questionable Performance Record

The report contains many recommendations for expanding the power and influence of the “Administration on Developmental Disabilities” (ADD), going so far as to propose that ADD be removed from the Administration for Children and families and put on par with other agencies within the U.S. Department of Health and Human Services (HHS). Such a move would position ADD with policymaking authority and greater funding.

VOR strongly objects to any increase in ADD funding, power or influence. As described herein, DD Act programs, under ADD oversight, have long been engaged in practices harmful to persons with developmental disabilities whose severe conditions require close, specialized care.

There is no question that ADD actively promotes the DD Act programs' closure activities. In a report released by ADD in February 2011<sup>1</sup>, the following recommendations were included

- Promote access to community living services (Olmstead/Dept. of Justice enforced) – “Develop and implement plans to close public and private institutions and segregated workshops” (p. 12)
- Collaboration – “ADD and the Administration on Aging should jointly plan and pool resources at the Federal and State levels while maintaining the DD Act values. Caution against taking on any values/programs that involve congregation and segregation” (p. 13).
- Community Living – “Keep people with disabilities out of congregate institutions” and “Harness the supports and influence of The Arc” (p. 14. Note: The Arc expressly supports the elimination of institutional supports).

ADD also promotes a culture that disrespects and disregards the input of families of ICF/MR residents, contrary to the DD Act. On at least two occasions, the current Commissioner has accused families who have selected ICF/MR supports for their medically fragile family members with profound intellectual disabilities as suffering from a “failure of imagination,” suggesting that these families are not creative enough to develop community placements for their family members, even when community placement may be life-threatening. Tragically, Commissioner Lewis fails to accept this possibility and apparently has no reservations about calling for closure of ICFs/MR.

## **B. Incomplete Representation of the Developmental Disabilities Community**

In Chairman Jonathon Young's letter of transmittal and in the report's executive summary, he describes individuals with developmental disabilities as “among the ranks of Americans who *graduate from high school, pursue post secondary education or training, enter the workforce, volunteer, and otherwise participate in the daily life of their communities.*” (*Emphasis added*). While this sentence is true, it leaves the reader with an incomplete and misleading description and understanding of the wide range of abilities present in the developmental disability community. Some individuals function at an extremely low level while others function at a higher level. Both deserve a safe place to live with supports and services essential to meet their needs.

ICF/MR residents **are marginalized and ignored by the NCD**. Residents of ICFs/MR are among the neediest, most fragile and most disabled members of our society. Nearly 80% of the nation's ICF/MR residents experience severe or profound intellectual disability, functioning at an infant or toddler's level although fully grown. They need substantial support in every aspect of life including walking, communicating, bathing, eating and toileting<sup>2</sup>. Challenges include epilepsy/seizure, speech/language impairment, severe visual impairment, profound hearing loss, blind, cerebral palsy, deaf, obsessive-compulsive disorder, bipolar, anxiety disorder, depression, schizoaffective disorder, psychosis, impulse control disorder, oppositional defiant disorder, panic disorder, intermittent explosive disorder, and criminal records. These

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<sup>1</sup> [http://www.envision2010.net/docs/Summary\\_Envision\\_Regional\\_Prioritization\\_Meetings.pdf](http://www.envision2010.net/docs/Summary_Envision_Regional_Prioritization_Meetings.pdf)

<sup>2</sup> “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>)

voiceless and vulnerable individuals will never graduate from high school, pursue post-secondary education or training, or enter the workforce (as understood by the public).

Medicaid certified and licensed ICFs/MR are often the best way to meet the needs of the most vulnerable of the population with an intellectual disability and developmental disabilities, providing them with comprehensive around-the-clock supports to assure their safety and enable them to live their lives to the fullest. As of June 30, 2009, the federal government helps fund and monitor 6,469 ICFs/MR that are home to 90,348 people, down 3% from 2008<sup>3</sup>. DD Act programs are using public funds to destroy the valuable and life sustaining ICF/MR level of care to the detriment of our nation's most fragile citizens. NCD, in its review of DD Act programs, fails to acknowledge this very real failing.

### **C. Misleading Statements Regarding Intent of Congress for the DD Act**

The letter of transmittal also states that the DD Act “established a set of programs to improve the lives of people with developmental disabilities (DD), to protect their civil and human rights, and to promote their maximum potential through *increased independence, productivity, and integration into the community.*” (*Emphasis added*).

Even acknowledging these laudable goals, nothing in the DD Act mandates or supports removing all people from the facilities in which they choose to live. Indeed, the DD Act validates the role of the individual and family in making choices based in individual need:

“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.”<sup>4</sup>

Congressional intent further confirms support for the provision of facility-based care based on individual choice and need:

“[the] goals expressed in this Act to promote the greatest possible integration and independence for some individuals with developmental disabilities not be read as a Federal policy supporting the closure of residential institutions. It would be contrary to Federal intent to use the language or resources of this Act to support such actions, whether in the judicial or legislative system.”<sup>5</sup>

For many former ICF/MR residents who have transitioned into the community, some against the wishes of their court-appointed family guardian, “integrated into the community” means living in a staffed residence with one caregiver on duty, providing complete care for three individuals with severe and profound intellectual disabilities often accompanied by one or a combination of other conditions. All residents must agree to outings to church, movies, a restaurant, a park, or no one goes, since only one caregiver is on duty. In many ways, they become prisoners in their fully integrated community home.

For persons with severe disabilities who are unable to self-advocate, and for persons with severe disabilities who have no active family involved in their care, an isolated home with one caregiver can be disastrous. The NCD report acknowledged this concern (see, p. 9). If a caregiver strikes or otherwise abuses a resident there is no one to see and no one to tell. Many residents are unable to communicate. They cannot report

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<sup>3</sup> Id. 2009 (<http://rtc.umn.edu/docs/risp2009.pdf>, p. vi).

<sup>4</sup> DD Act, 42 U.S.C. 15001(c)(3)(1993) (Findings, Purposes and Policies; *italicized language added in 2000*)

<sup>5</sup> House Energy and Commerce Committee Report No. 103-378, November 18, 1993 (to accompany H.R. 3505, the Developmental Disabilities Act Amendments of 1993)

the abuse; they cannot speak a word. Rights associated with living in the community with “independence and freedom” must be balanced with the right to treatment. Author E. Fuller Torrey said it best in his book, “The Insanity Offense” (examining the tragedy of our treatment of people with mental illness):

“[Individuals who face tragedy following their release from specialized facilities can be described as] dying with one’s rights on.” (p. 90, quoting Darrold Treffler)

“The paramount civil right of the patient should be that of adequate treatment.” (p. 9, quoting Stephen Rachlin)

“The right to treatment is more fundamental than unrestricted liberty. If we do not provide adequate treatment, we offer the patient no freedom at all.” ( p. 161, quoting Stephen Rachlin)

The DD Act programs must and can do better. “Rising expectations” – the expectation of resident choice, family decisionmaking, and the provision of adequate care – are where Congressional (per legislative history and law) and family/guardian expectations merge.

#### **D. Promotes Currently Popular But Misguided and Harmful Ideological Policies**

We strongly submit that community **and** congregate care options are necessary to properly serve all individuals with ID/DD.

The following conclusions are representative of many throughout the report that we find objectionable and biased:

“The changes and shifts in [the DD Act] language and focus reflect the rising expectations that led individuals with DD and their families out of isolation and institutionalization into an era that emphasizes inclusion, independence and family and community supports.” (Report, p. 94)

“Instead of being institutionalized, marginalized, and forgotten, people with DD have made huge steps in taking their rightful place in society – in schools, workplaces, and the public square, and even within their own families.” (Report, p. 181)

“Through class action lawsuits and other legal and advocacy approaches, [P&A programs] have been a major factor in the closure of some institutions. . . .” (Report, p. 133)

“P&A programs provide essential legal representation and were integral to both deinstitutionalization and enforcement of IDEA but lack of resources undermines their effectiveness.” (Report, p. 182)

It does not appear that NCD’s research included a visit to an ICF/MR to meet with staff, visit with residents, or speak to families and guardians. There is reference to a “panel of stakeholders” who were consulted monthly (Report, p. 14), but these persons are not identified and it is unlikely that a stakeholder who is satisfied with ICF/MR care was included.

Our members’ loved ones are not isolated, marginalized or forgotten. The report is incomplete and biased because it has not given equal weight to and opportunity for the input of parents and guardians of individuals with severe and profound levels of developmental disabilities who cannot self-advocate.

The report lists deinstitutionalization and closure of Medicaid licensed and certified facilities as positive outcomes of P&A work. Nothing could be farther from the truth. The report is wrong. Tragedies in

community-based settings - from physical, emotional, and financial abuse, neglect and even death - are widespread (see <http://www.vor.net/abuse-and-neglect>).

Many preventable tragedies are associated with a zest to move to a "community for all" vision for people with developmental disabilities without adequately considering the ramifications of separating vulnerable people from specialized care and then doing away with a critical safety net (a/k/a deinstitutionalization). The lessons learned from more than 25 states should cause policymakers and lawmakers to halt appropriations for deinstitutionalization of persons with developmental disabilities from their Medicaid certified and licensed homes.

#### **IV. Conclusion**

VOR objects to the conclusions and recommendations found in the NCD report: that Administration on Developmental Disabilities (ADD) and the DD Act programs should have increased funding and greater policymaking powers for persons with DD.

**Instead of expanded funding and greater policymaking powers, VOR supports meaningful reform aimed at ensuring that the DD Act programs embrace residential choice and family decisionmaking as required by the DD Act and Congressional intent.**

It has been 11 years since the Congress last reauthorized the DD Act. Some of the DD Act programs, through lobbying, class action lawsuits and other destructive tactics to eliminate the ICF/MR option – have been violating the letter and intent of the Act in ways that have been harmful to the vulnerable people the DD Act is intended to help. DD Act deinstitutionalization practices force the transfer of thousands of vulnerable individuals from specialized ICFs/MR that are uniquely suited to meet their extreme and intensive needs, often resulting in predictable tragedies.

**VOR urges Congress to take the following actions:**

- A.** Schedule public hearings on the DD Act as soon as possible, providing opportunity for affected individuals and their families to testify.
- B.** Amend the DD Act to enforce DD Act program adherence to residential choice, as is clearly supported by Congressional intent and the U.S. Supreme Court's Olmstead decision:  
  
"No funds expended for any Developmental Disabilities Assistance and Bill of Rights Act program may be used to effect closure of any Medicaid-certified Intermediate Care Facility for Persons with Mental Retardation or to support entities engaged in activities to close any such facility."
- C.** Enact the provisions of H.R. 2032 to require DD Act programs to notify the residents of an ICF/MR or, where appointed, their legal representatives (defined to include legal guardians and conservators) before filing a class action and provide them with a time-limited opportunity to opt out of the class action.
- D.** Limit the reauthorization cycle to three years.

**Thank you for your consideration. For more information, contact Tamie Hopp, VOR's Director of Government Affairs and Advocacy at 877-399-8467 or [thopp@vor.net](mailto:thopp@vor.net).**