



“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.” (U.S. Supreme Court, *Olmstead v. L.C.*)

WASHINGTON STATE:

Why Congress Should Care About the ICF/MR Program and the People It Serves **The Human Consequences of the DD Act Programs’** **Ideologically-Based Attacks on ICF/MRs**

The Developmental Disabilities Assistance and Bill of Rights Act (DD Act)

The DD Act authorizes three primary grant programs designed to “assure that individuals with developmental disabilities and their families participate in the design of and have access to needed community services, individualized supports, and other forms of assistance that promote self-determination, independence, productivity, and integration and inclusion in all facets of community life. . . .”

Congressional Intent and the Role of ICFs/MR in the Continuum of Care

As clarified by Congress, the DD Act’s support for these goals is “not [to be] read as a Federal policy supporting the closure of residential institutions.” In both statute and report language, Congress made it clear that individuals and their families, not the DD Act programs, were the “primary decisionmakers” regarding needed and desired services, “including regarding choosing where the individuals live.” Congress expressly cautioned, in the House Energy and Commerce Committee report accompanying this language, “that 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.”

Why did the Congress support the continuation of residential institutions? The answer lies in the population who reside in such facilities and the care they receive. Residents of ICFs/MR are among the neediest, most fragile and most disabled members of our society. They need substantial support in every aspect of life including walking, communicating, bathing, eating and toileting. Nearly 80% (79.3%) of all ICF/MR residents experience severe or profound intellectual disabilities, functioning at an infant’s level although fully grown; they also endure multiple disabilities, chronic medical conditions and/or behavioral challenges. Many also have seizure disorders, behavior problems, mental illness, visual or hearing impairments, or have a combination of these conditions.

ICFs/MR are often the best way to meet the needs of the most vulnerable of the population with intellectual 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.

Currently, the federal government helps fund and monitor 6,381 ICFs/MR that are home to 93,164 people.

Additional Resources and Legislative Recommendations

The full report on which this document is based is available online at:

<http://www.vor.net/images/stories/pdf/TaskForceReport.doc>.

Recommendations for DD Act reform can be found at the end of this document.

WASHINGTON STATE: All three primary DD Act programs pursue activities which violate Congressional intent

I. DISREGARD FOR FAMILY INPUT, IN VIOLATION OF THE DD ACT'S REQUIREMENT THAT INDIVIDUALS AND FAMILIES BE THE "PRIMARY DECISIONMAKERS"

A. Organizational Priorities

1. WA State Developmental Disabilities Council (DDC) continues to promote Policy No. 103 – Downsizing and Closure of All Residential Habilitation Centers – in spite of requests by Council members to revisit this policy. (Policy No. 103, November, 1991)
2. The sole RHC advocate currently serving on the Council has been continually rebuffed by the Council leadership in his attempts to discuss and reach consensus as to the types of services and supports within the state of WA. (Correspondence May 23, 2009)
3. "Continue the process of consolidating the RHCs [ICFs/MR] and redirect the resources to community supports and services that enable people with developmental disabilities to live and work in their community." (Washington State DD Council, Legislative Agenda Brochure, 2006)
4. Washington Protection & Advocacy, now known as Disability Rights Washington, follows a similar pattern as the DDC. Their Priorities list includes "**Choice & Inclusion**" "People

with disabilities will exercise their rights consistent with the principles of inclusion & choice, **as they desire**". (Current Priorities of Disability Rights Washington)

Issue: DRW repeatedly work to have residents removed from the RHCs – against their wishes.

5. DRW Community Imperative: "In fulfillment of human rights and in securing optimum opportunities for growth, all people, regardless of the severity of their disabilities are entitled to community living." DRW goes beyond "entitled to community living". Their Director of Public Policy has repeatedly testified in favor of closure of state facilities, disregarding the residents, parent/guardians desire to remain at the facility. (House and Senate Hearing, January-April, 2009)

B. Litigation

In 1996, the Washington State P&A represented People First of Washington in a proposed class action lawsuit against Rainier School seeking community integration of Rainier residents. The families and guardians of the residents successfully intervened and prevented certification of the class. (People First of Washington v. Rainier Residential Habilitation Center).

C. Legislative Advocacy

1. DDC promoted an advocacy effort consisting of "Blue Cards" mailed to the Governor and all Legislators in an attempt to draw supports away from the RHCs. (December 2008)
Issue: Community expansion is a need in WA State. However, it should not be at the expense of another segment of the DD population.
2. DDC has made substantial grants through sole source contracts to advocacy groups that support the closure of all institutions. These are federal dollars spent to close programs that are federally funded. (DDC Policy No. 416, November, 2000)
3. DDC testified at hearings against HB1407 – Residents Rights Bill. The intent of this bill is to extend basic rights to residents of intermediate care facilities for persons with developmental disabilities. Basically, it gives residents the same guaranteed rights as residents in nursing facilities. DDC initially agreed to work with the sponsors to broaden the bill to include other individuals in supported living. However, their "feet dragging" made efforts impossible this session. DDC's Rationale: Residents of ICFs/MR are protected federally – there is no need for state protection.

DDC testified that such a bill would "tie the hands" of DSHS, should the Department decide to consolidate or close an RHC.

DDC has agreed to re-visit the bill and its efforts before session resumes in January, 2010.

4. DRW worked in tandem with the DDC regarding testimonies against HB 1407 – They contended Residents’ Rights were protected federally – No need for state intervention. Then, a change of heart, looking to expand such rights to all individuals in supported living. They agreed to work with the bill’s sponsor, but delayed any pertinent discussion for this session. (House & Senate Hearings, January-April, 2009)
5. DRW is charged by their Mission & Values statements to “...remove barriers which prevent access to full participation in community life”.

Issue: Where is the authorizing language to define barriers as state institutions/facilities?

Issue: Does a so-called “National Trend” give DRW the right to advocate & litigate without the concurrence of those directly involved in such actions?

II. DEINSTITUTIONALIZATION – ICFs/MR CLOSURE ACTIVITIES

A. Organizational priorities

1. DDC signed on to an effort to consolidate & close the RHCs – “Coalition to Consolidate DD Institutions”. This was done without bringing the issue to a Council vote. Ed Holen, Executive Director of DDC signed on using DDC Policy 103 (November, 1991) as his directive. (February, 2009)

2. DRW, through their Executive Director, Mark Stroh, signed on to an effort to consolidate and close the RHCs – “Coalition to Consolidate DD Institutions”. (February, 2009)

Issue: This was done while clients, parent/guardians were testifying before the House and Senate trying to maintain the homes of their loved ones. Not once did any representative of the DRW come to a resident, parent/guardian and ask if they wanted the facility closed. These residents are the same individuals whose rights DRW is pledged to protect.

B. Legislative Advocacy

1. During the last Legislative Session, DDC Executive Director and Staff Members repeatedly testified in favor of RHC closures. (House & Senate Hearings, January-April 2009)
2. DRW echoed the testimonies of the DDC regarding the proposed closures of the state facilities, specifically Yakima Valley School. (House & Senate Hearings, January-April, 2009)

III. OUTCOMES: DISREGARD FOR INDIVIDUAL NEED AND NEGATIVE OUTCOMES FOLLOWING DEINSTITUTIONALIZATION / DISCRIMINATION AGAINST PEOPLE WITH SEVERE MR/DD

“Roads to Community Living” is the Washington State version of the federal “Money Follows the Person” grant. DSHS, DDC & DRW have successfully moved a number of individuals into the Community. The state financial shortfall has now created funding issues for these individuals. Day 366 has arrived and their continued funding is an issue.

“Before the late 1990s, Medicaid waivers were more widely available. But since changes were made to the program several years ago, the need vastly exceeds the availability.” (Services in Short Supply, Maureen O’Hagan, Seattle Times, April 27, 2008)

Issue: Residential Care Providers are experiencing cuts of 3%-4% due to the 2009-2011 budget. This is creating a strain on the providers in the Community.

Recommended Reforms

In light of these activities by DD Act programs – all of which violate Congressional intent and bring harm to the very constituents they are charged to advocate for and protect, VOR calls on Congress to take the following actions aimed at assuring that DD Act program recipients carry out the Act’s mandate to respect choice in residential settings and family decision-making:

- 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.

For More Information:

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