

# **The 2007 Reauthorization of the Developmental Disabilities Assistance and Bill of Rights Act**



## **The Need for Immediate Reforms**

**Submitted by  
Mary McTernan, Ph.D.  
President  
VOR**

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**VOR**  
**(Voice of the Retarded)**  
**836 S. Arlington Heights Rd., #351**  
**Elk Grove, IL 60007**  
**605-399-1624 voice**  
**605-399-1631 fax**  
**Tamie327@hotmail.com**  
**http://www.vor.net**

**Mary E. McTernan, Ph.D., President**

### **A Message from VOR's President**

My 41 year-old daughter, Mary Elizabeth, has profound mental retardation, with significant physical and medical disabilities. She functions at the level of less than one year old and needs fulltime help for all her daily needs, from toileting to dressing to eating. Mary Elizabeth resides in a community group home, but each and every day returns to her former home – a state-operated ICF/MR – for physical therapy, swimming in a therapeutic pool, socialization, community outings with facility residents, and nursing care. Mary Elizabeth's successful community living is due in large part to her continued interaction with the ICF/MR's nurses, direct care staff and residents – people she has known most of her life.

Mary Elizabeth is not alone in terms of her level of disability and her reliance on ICF/MR care for continued health, safety and happiness. She represents thousands of others whose lives depend on the continued existence of ICF/MR options for people with severe and profound mental retardation, who also have chronic medical conditions and/or severe behavioral challenges.

In addition to being Mary's Elizabeth's mother, I am also President of VOR. I agreed to serve VOR because this organization supports residential and service choice. VOR is a national advocacy organization that speaks for all individuals with mental retardation and their families. We recognize that the availability of a full array of quality residential services and supports for people with mental retardation, through all stages of life, based on choice and need, with full family involvement, is a common sense policy that leads to good outcomes.

We respectfully request your consideration of VOR's position on behalf of our nation's most vulnerable citizens and the proposed reforms to the 2007 Developmental Disabilities Assistance and Bill of Rights Act (DD Act). We submit that some DD Act funded programs are violating some of the key purposes and policies of the Act and, as a result, are doing harm to people with severe and profound mental retardation.

Thank you for your thoughtful consideration. Remember, Americans who can't help themselves due to no fault of their own are dependent upon the good will of the Congress.

***Mary E. McTernan, Ph.D.***

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## Executive Summary

### **The 2007 Reauthorization of the Developmental Disabilities Assistance and Bill of Rights Act: The Need for Immediate Reforms**

In 2007, for the first time in seven years, Congress is required to consider the reauthorization of programs receiving federal funding under the Developmental Disabilities Assistance and Bill of Rights Act (DD Act).

While the DD Act's policy endorses residential choice, some Protection and Advocacy agencies (P&A's), through class action litigation, act to eliminate one of those choices – Medicaid-certified and funded Intermediate Care Facilities for Persons with Mental Retardation (ICFs/MR). These practices force the transfer of thousands of individuals from specialized ICFs/MR that are uniquely suited to meet their extreme needs. P&A lawsuits, for example, have been filed without regard to the choices of the people affected and their families/guardians. The resulting closures of some ICFs/MR have led to higher incidences of abuse, neglect and death of people with severe and profound mental retardation, who also have other debilitating physical, medical and/or behavioral disabilities. What's more, when P&A (funded by the U.S. Department of Health and Human Services (HHS), as authorized by the DD Act) sues to close an ICF/MR (funded and certified by HHS), the lawsuit could be titled HHS v. HHS – an absurd use of federal dollars.

VOR urges Congress to adopt the following reform proposals aimed at assuring that DD Act program recipients carry out the Act's mandate to respect choice in residential settings and family decisionmaking:

- A.** Freeze (level fund) DD Act program funding to give Congress time to review the programs and consider reforms.
- B.** Pass H.R. 3995 to require that federally-funded organizations, including P&A, notify residents of Medicaid funded and certified ICFs/MR before a class action is filed, and provide a time limited opportunity for residents, or where one has been appointed, their legal guardians, to opt out of the lawsuit.
- C.** An HHS audit of how DD Act programs are working and whether they are respecting family choice and the *Olmstead* decision, to be submitted to relevant House and Senate committees within one year.
- D.** A three year reauthorization so that the Congress can more closely monitor the effectiveness of DD Act policy and activity and how HHS is overseeing it.

VOR also calls on Congress to require that CMS conduct a study of whether states are offering people freedom of choice between an ICF/MR and Home and Community Based Services (HCBS) waiver settings, as required by Medicaid law and regulation (42 U.S.C. §1396n(c)(2)(C), 42 C.F.R. §441.302, and 42 C.F.R. §441.303(d)).

***Thank you for your thoughtful consideration of VOR's DD Act reform proposals.***

**About VOR:** Voice of the Retarded is a national organization advocating for the right of individuals with MR/DD and their families to choose from among a full array of high quality residential and other support options. For more information, please contact Tamie Hopp, Executive Director and Director of Government Relations and Advocacy at 605-399-1624 (direct); 410-757-1VOR(1867) (VOR Washington, D.C. office); or [Tamie327@hotmail.com](mailto:Tamie327@hotmail.com).

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**For More Information**

**Developmental Disabilities Assistance and Bill of Rights Act (DD Act):** →  
<http://www.vor.net/DDAct2007.html>

**More information about VOR:** →  
<http://www.vor.net>

**DD Act, 42 U.S.C. 15029(a), 15045, and 15066(a)(1):**  
<http://www.vor.net/DDAct2007.html> →

# **The 2007 Reauthorization of the Developmental Disabilities Assistance and Bill of Rights Act:**

## **The Need for Immediate Reforms**

### **I. INTRODUCTION**

In 2007, for the first time in seven years, Congress is required to consider the reauthorization of programs receiving federal funding under the Developmental Disabilities Assistance and Bill of Rights Act (DD Act). The DD Act needs to be reauthorized, but it also needs to be amended to make sure its purposes are being carried out.

VOR is a national organization that advocates for the right of individuals with mental retardation and developmental disabilities and their families to choose from among a full array of high quality residential and other support options.

While the DD Act's policy also endorses residential choice, some federal funds allocated to implement the DD Act are used to eliminate one of those choices: Intermediate Care Facilities for Persons with Mental Retardation (ICFs/MR). ICFs/MR are often the best way to meet the needs of the most vulnerable of the population with mental retardation and developmental disabilities.

The reauthorization process will allow Congress a rare opportunity to review DD Act funding streams. There is a clear disservice being done to some of our most vulnerable, least able citizens under the auspices of DD Act programs.

With this presentation, VOR documents for Members of Congress federal law as it relates to residential choice, the people being served by ICFs/MR, the services they receive, the disconnect between DD Act policy and practice, and the sometimes tragic outcomes that result. The presentation concludes with suggestions for much needed reform to be written into the 2007 DD Act reauthorization.

### **II. LACK OF CONGRESSIONAL AND AGENCY OVERSIGHT**

In 2000, when the Congress last reauthorized the DD Act, it amended the Act to extend the reauthorization period from three years to seven. *The long reauthorization period resulted in little or no congressional oversight regarding the effectiveness of DD Act programs for this extended period of time.* VOR believes that, as a result, the purposes of the DD Act and the interests of a highly vulnerable population have been seriously compromised. In many cases these programs have undermined the structured care which many individuals with complex, severe disabilities require for their well-being and survival.

**For More Information**

Since 2000, the House Energy and Commerce Committee’s membership has changed by 51%; the Senate Health Education Labor and Pensions Committee has changed by 57%. The 2007 reauthorization provides an opportunity for the newly reconstituted Senate and House committees to review in depth how effective the DD Act programs are in carrying out their congressional mandate for people with mental retardation and developmental disabilities. In particular, Congress should assess the impact that the programs are having on people with severe and profound mental retardation. Following this review, Congress needs to adopt meaningful reforms.

**Section III**, which follows, provides background information supporting our case for immediate reform to key provisions within the DD Act. **Section IV** (p. 10) sets forth VOR’s recommendations for immediate reform.

**III. THE NEED FOR IMMEDIATE REFORMS**

- A.** The people served in ICFs/MR
- B.** The services people receive in ICFs/MR
- C.** An overview of federal law in support of choice
- D.** Abuse and neglect in community settings
- E.** Protection & Advocacy lawsuits: Questionable results and a demonstrated lack of family involvement

**A. The people served in ICFs/MR**

Residents of ICFs/MR are among the neediest, most fragile and most disabled members of our society. They need support in every aspect of life including walking, communicating, bathing, eating and toileting. Nearly 80% (79.3%) of all ICFs/MR residents experience severe and profound mental retardation; they also endure multiple disabilities, chronic medical conditions and/or behavioral challenges. Many of these people also have seizure disorders, behavior problems, mental illness, are visually-impaired or hearing-impaired, or have a combination of these conditions.

Currently, 7,400 ICFs/MR are home to 129,000 people.

**VOR Position – Our Family Members: People with Severe and Profound Mental Retardation:**

<http://vor.net/PeoplewithSPMR.html> →

**Characteristics of Residents of Large Facilities (Chart):**

<http://rtc.umn.edu/docs/risp2004.pdf> (page 31). →

**Background and Milestones – ICFs/MR:**

<http://www.cms.hhs.gov/CertificationandCompliance/downloads/ICFMRBackground.pdf> →

**For More Information**

**Background and Milestones – ICFs/MR:** →

<http://www.cms.hhs.gov/CertificationandCompliance/downloads/ICFMRBackground.pdf>

**ICFs/MR: Meeting the Long Term Care Needs and Maximizing the Potential of Individuals with MR/DD:**

<http://vor.net/ICFMRBackground.html> →

**Characteristics of Residents of Large Facilities (Chart):** →

<http://rtc.umn.edu/docs/risp2004.pdf> (page 31).

**An invitation to visit an ICF/MR:** →

<http://vor.net/VisitInvite.html>

**Northern Virginia Training Center:** →

<http://www.nvtc.dmhmr.sas.virginia.gov/contacts.asp>

**B. The services people receive in ICFs/MR**

**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 some ICF/MR residents the provision of professional support and health care is required for their very survival.

**An invitation to visit an ICF/MR**

To fully appreciate the people served, their extreme needs, and the professional and compassionate care and training they receive, we encourage Members of Congress and their staffs to visit ICFs/MR in your districts, or the Northern Virginia Training Center (NVTC), located in Fairfax, Virginia (Mark Diorio, Director; 703-323-4000). VOR members are happy to arrange for a tour and introduce you to their family members with mental retardation, or you can arrange a tour directly with the facility. You will be warmly welcomed.

**For More Information**

**DD Act, 42 U.S.C. → 15001:**  
<http://www.vor.net/DDAct2007.html>

**Visit <http://www.vor.net/DDAct2007.html> for additional DD Act resources, including:**

- ✓ Link to DD Act
- ✓ 1993 House Committee report language re: Purposes and Policies
- ✓ "Deinstitutionalization is not mandated by the DD Act," August 2006.

**Olmstead decision resources: →**  
[http://www.vor.net/olmstead\\_resources.htm](http://www.vor.net/olmstead_resources.htm)

**Justice Ginsburg, → majority opinion:**  
<http://supct.law.cornell.edu/supct/pdf/98-536P.ZS>

## **C. An overview of federal law in support of choice**

Federal law is consistent with common sense: Like any other citizen, people with mental retardation and their families/guardians have the right to choose where to live.

### **The Developmental Disabilities Assistance and Bill of Rights Act of 2000**

Nothing in the DD Act mandates or supports removing people from the facilities in which they choose to live. Indeed, the Act validates the role of the individual and family:

"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." DD Act, 42 U.S.C. 15001(c)(3)(2000) (*Findings, Purposes and Policies*).

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

"[T]he Committee would caution 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" (House Energy and Commerce Report No. 103-378, Nov. 18, 1993, pages 7-8 (to accompany H.R. 3505, Developmental Disabilities Assistance and Bill of Rights Act Amendments of 1993, Section-by-Section Analysis, Section 3, adding Purposes and Policies to Findings)).

### **The Olmstead decision**

Contrary to some advocates' representations, Olmstead does **NOT** mandate deinstitutionalization of every disabled person. The Supreme Court in Olmstead very clearly supports choice in residential options, finding that the decision of where someone is served must be grounded on need, choice and available resources:

"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. 2185, 2187 (1999).

**For More Information**

**Justice Kennedy, concurring opinion:**  
<http://supct.law.cornel.edu/supct/pdf/98-536P.ZC1> →

**Justice Ginsburg, majority opinion:**  
<http://supct.law.cornel.edu/supct/pdf/98-536P.ZS> →

**Visit [http://www.vor.net/olmstead\\_resources.htm](http://www.vor.net/olmstead_resources.htm) for additional Olmstead information, including:**

- ✓ VOR Olmstead Amicus Brief
- ✓ Olmstead and Choice – Outline
- ✓ What Olmstead is Not
- ✓ Olmstead and Guardianship

**Compliance with State Plan and Payment Provisions, 42 U.S.C. §1396n** (see, <http://www.gpoaccess.gov/uscode/search.html>) →

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*)

Justice Kennedy concurred:

“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.” 119 S. Ct. at 2191 (Kennedy, *Concurring*).

According to the Supreme Court, institutionalization is “unjustified” and community placement is required and only appropriate when:

- (a) “The State’s treatment professionals have determined that community placement is appropriate;
- (b) The transfer from institutional care to a less restrictive setting is not opposed by the affected individual; and
- (c) The placement can be reasonably accommodated, taking into account the resources available to the State and the needs of others with mental disabilities.” Olmstead v. L.C., 119 S. Ct. 2185, 2181 (1999).

**Medicaid law**

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).

## **For More Information**

**Code of Federal Regulations** → Part 441 Services: Requirements and Limits Applicable to Specific Services; Subpart G, Home and Community Based Services: Waiver Requirements (*see*, <http://www.gpoaccess.gov/cfr/index.html>)

## **ABUSE AND NEGLECT IN COMMUNITY SETTINGS: RESOURCES**

**VOR's Abuse and Neglect document:**  
[http://vor.net/abuse\\_neglect.htm](http://vor.net/abuse_neglect.htm)

***Closing the Gap: A National Blueprint to Improve the Health of Persons with Mental Retardation***, U.S. Surgeon General (2002):  
<http://www.vor.net/DDAct2007.html>

**Special Olympics Health Research**  
("Special Olympics research has found that health care professionals are not providing access to quality health care for people with intellectual disabilities and people with intellectual disabilities have some of the worst health care of any minority population in America"):  
<http://www.vor.net/DDAct2007.html>

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).

Many states **routinely** do not follow the law with regard to advising eligible individuals or their legal guardians the choice between HCBS waiver and ICF/MR services. Furthermore, CMS has not held states accountable to upholding the choice law, despite citizen complaints. In addition to DD Act program reform, VOR also requests that Congress put in place reforms that help ensure that established law with regard to the provision of choice is followed. ICF/MR and HCBS-eligible individuals must be advised of their right of choice under Medicaid law.

## **D. Abuse and neglect in community settings**

Sadly, abuse and neglect of people with mental retardation continues to occur in both institutional and community settings. Simply residing in the community is no guarantee of quality care. Quality care is not a function of where one lives but of the skills and commitment of the staff and of proper oversight.

The cause of compromised quality in community-based settings for people with mental retardation 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.

These concerns are widespread. In 30 states and the District of Columbia, reports of **systemic** abuse, neglect and death have appeared in newspapers, state audits, and scholarly journal articles. Congress, the U.S. Surgeon General, the General Accountability Office and CMS have also cited serious concerns regarding compromised quality in community settings. For example, 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." Financial exploitation was 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."

**For More Information**

**ABUSE AND NEGLECT IN COMMUNITY SETTINGS: RESOURCES (continued)**

**Quality Oversight Compared: A comparison between ICFs/MR and HCBS Waivers (2004):**  
<http://www.vor.net/QualityCompared.html>

**Bibliography of 72 peer reviewed studies about the abuse of children with developmental disabilities (2001):**  
<http://cfrwww.social.uiuc.edu/respract/biblio.pdf/abuseofdisabled.pdf>].

**Federal Oversight of Growing Medicaid HCBS Waivers Should be Strengthened,** GAO-03-576 (June 2003),  
<http://www.gao.gov/new.items/d03576.pdf>.

**Letter from Senators Grassley and Breaux, re: poor HCBS quality:**  
<http://grassley.senate.gov/releases/2003/p03r07-07a.htm>

**HCBS Quality Framework and Communications, Centers for Medicare & Medicaid Services:**  
[http://www.cms.hhs.gov/HCBS/04\\_CMSCommunications.asp](http://www.cms.hhs.gov/HCBS/04_CMSCommunications.asp)

**PROTECTION AND ADVOCACY**

**Admin on DD** →  
<http://www.acf.hhs.gov/programs/add/states/pas.html>.

While similar problems occur in ICFs/MR, state and federal scrutiny regarding ICF/MR care guards against long-term, systemic problems. ICFs/MR are held to 378 specific standards ("Conditions of Participation") annually. In contrast, HCBS waiver programs are reviewed only every 3-5 years and are **not** subject to uniform quality assurance standards. So, while there are good community programs, there are many others that fail to provide high quality care. The current system of oversight often fails to identify these "bad apples" until tragedy occurs.

**E. Protection and Advocacy lawsuits: Questionable results and a demonstrated lack of family involvement**

**Statement of the problem**

The activities of some federally-funded DD Act programs have contributed to higher abuse, neglect and death of some individuals with severe and profound mental retardation. Foremost among these activities are class action lawsuits brought by Protection and Advocacy (P&A) that eliminate specialized services needed by many of our nation's most vulnerable citizens, forcing the transfer of these individuals over the wishes of their parents and guardians to community programs that are often unprepared to safely serve their specialized needs. Many of these problems could be avoided if P&A consulted with and secured the approval of the families and guardians of people living in large facilities before they filed class action suits on their behalf. Instead, P&A's routinely ignore family/guardian input and choice.

**P&A systems' mandate**

State-based P&A systems receive federal funding to "protect the legal and human rights of individuals with developmental disabilities" by "pursuing legal, administrative, and other appropriate remedies or approaches." Some P&A's have interpreted their charge to include class action lawsuits against ICFs/MR (42 U.S.C. §15041 and 42 U.S.C. §15043(a)(2)(A) (2000) (<http://www.vor.net/DDAct2007.html>).

**P&A funding since the last reauthorization**

P&A Funding, FY 2000 – FY 2006 (in millions)

FY 2000	FY 2001	FY 2002	FY 2003	FY 2004	FY 2005	FY 2006
\$28.11	\$33.0	\$32.34	\$36.263	\$38.416	\$38.107	\$37.928

## For More Information

### PROTECTION AND ADVOCACY LAWSUITS

**A list of P&A class action lawsuits:** →  
<http://vor.net/classactions.htm>

**VOR's Abuse and Neglect document:** →  
[http://vor.net/abuse\\_neglect.htm](http://vor.net/abuse_neglect.htm)

**Shavell, Strauss, and Day Mortality Study,** →  
<http://www.lifeexpectancy.com/articles/jds.pdf>.

**Note:** The 2005 Shavelle, et al., study is one in a series of comparative mortality studies involving people with DD and deinstitutionalization (see, <http://www.lifeexpectancy.com/articles.shtml> - link, "Comparative Mortality").

**DD Act, 42 U.S.C. 15024(c)(5)(B)(iv):**  
<http://www.vor.net/DDAct2007.html> →

## Class action lawsuits: HHS v. HHS

Since the late-1970s, there have been at least 25 P&A-initiated class action lawsuits against ICFs/MR with the express or implied purpose of closure. Since 2000, the date of the last reauthorization, eight such lawsuits have been filed and an additional two have been settled. As a result of all these lawsuits, at least 21 ICFs/MR have closed, resulting in the forced transfer of thousands of individuals from their homes.

P&A class action lawsuits against ICFs/MR are funded by the U.S. Department of Human Services (HHS) through grants from the Administration on Developmental Disabilities, an agency within HHS. Most if not all residential facilities targeted by P&A class action lawsuits are funded and certified by CMS, also an agency within HHS. In these lawsuits, HHS is both plaintiff and defendant – a waste of taxpayer funds!

### Tragic consequences

The closures of ICFs/MR as a result of P&A class action suits have often had tragic consequences, with both mortality studies and media stories documenting systemic abuse, neglect and death (see e.g., Robert Shavelle, David Strauss and Steve Day, "Deinstitutionalization in California: Mortality of Persons with Developmental Disabilities after Transfer into Community Care, 1997-1999," *Journal of Data Science* 3(2005), 371-380: Following a class action lawsuit by California's P&A agency, more than 2,000 persons with developmental disabilities transferred from California institutions into community care during 1993 to early 1996. Researchers found a "corresponding increase in mortality rates by comparison with those who stayed behind . . . a 47% increase in risk-adjusted mortality over that expected in institutions.")

In the meantime, the number of people on waiting lists for services continues at high levels. When a facility is closed, the service system often loses the largest, most experienced provider, exacerbating a state's waiting list problem.

### Lack of communication with families

The policy provisions of the DD Act state that the individuals with developmental disabilities and their families – not the P&A's – are the primary decisionmakers regarding the services and supports they receive, including residential options:

"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." DD Act, 42 U.S.C. 15001(c)(3)(2000) (*Findings, Purposes and Policies*).

**For More Information**

***Protection and Advocacy Agencies: Involvement in Deinstitutionalization Lawsuits on Behalf of Individuals with Developmental Disabilities***, GAO-03-1044:  
<http://www.gao.gov/news/items/d031044.pdf>

**Family testimonials from California, Kentucky, Ohio, Florida, Illinois, Arkansas, Pennsylvania, and Maryland**, speaking to state P&A's' lack of respect for the parents, families and guardians, along with fervent efforts to close large ICFs/MRs, are available at  
<http://vor.net/FamilyTestimonials.htm>.

On its face, this policy makes good sense. It is based on the premise that the power of informed decisionmaking best rests with individuals and their families, and not with the DD Act funded entities. Many people with severe and profound mental retardation benefit from having a loved one who knows and cares about them serve as a legally-appointed guardian. The law appoints guardians to make fundamental decisions on behalf of their family members, recognizing that families often know best when the individuals are not able on their own to make life and death decisions.

Despite this common-sense notion and the clarity of Congressional intent, P&A programs routinely do not consult with families and guardians *before* filing suit. Generally, P&A's only comply with the notice requirements of the federal rules of civil procedure, which require notice to families and guardians only *after a proposed settlement* has been reached. Here are some examples.

- ❖ In **California**, P&A brought suit irrespective of the fact that 98% of the developmental center family/guardian survey respondents opposed P&A representation of their family members (Coffelt v. Department of Developmental Services, No. 91-6401 (Ca. Super. Ct. Jan. 1994).
- ❖ In **California**, in "Coffelt II" (Capitol People First, et al. v. California Department of Developmental Services, 2002), P&A challenged intervention efforts by parent/guardian representatives, arguing, "As a matter of substantive law, parents and guardians of institutionalized persons have different and potentially conflicting interests on matters pertaining to their child's or ward's constitutional or statutory rights to liberty and due process." The Court rejected P&A's challenge.
- ❖ In **Kentucky**, families and guardians have filed a lawsuit to oppose a settlement agreement between P&A and the State that calls for transferring individuals from state ICFs/MR, and then closing those beds to future admissions.
- ❖ In **Ohio**, more than 31,000 people, including families and guardians, successfully opposed a proposed settlement between the P&A (OLRS) and the State to eliminate entirely the ICF/MR program. "For the past sixteen years, families of individuals who chose to live in state-operated and private ICFs/MR, wrote to OLRS, asking that their loved ones be removed as part of the class . . . Shouldn't families and guardians be allowed a more active voice in litigation involving their family members with mental retardation?" (Ohio League for the Mentally Retarded (OLMR), a statewide family/guardian association, comments on OLRS state plan, June 2006).
- ❖ In **Florida**, families sought intervention in a P&A lawsuit that expressly calls for the closure of public ICFs/MR. Shortly after filing the lawsuit in 1998, the Florida P&A responded to a family's concern that their loved one may be transferred from a Florida facility by saying in a letter, "Florida's Developmental Services Institutions, constitute a despicable way for government and society to treat people who happen to have a developmental disability."

**For More Information**

**Family testimonials** →  
from **California, Kentucky, Ohio, Florida, Illinois, Arkansas, Pennsylvania, and Maryland**, speaking to state P&A's' lack of respect for the parents, families and guardians, along with fervent efforts to close large ICFs/MRs, are available at <http://vor.net/FamilyTestimonials.htm>.

- ❖ In **Illinois**, family guardians, on behalf of their family members, are seeking intervention in a P&A lawsuit that threatens the closure of private ICFs/MR with more than 9 beds.
- ❖ In **Arkansas**, families successfully intervened and challenged a P&A legal attempt to make admissions to state ICFs/MR more onerous for families by requiring court hearings for all admissions and annual court hearings to consider whether state-center residents should be discharged. This proposed process would have undermined the role of families and guardians, an apparent P&A objective in this case.
- ❖ In **Pennsylvania**, families of Western Center residents filed a lawsuit following the center's closure due to a P&A lawsuit. In addition to other claims, the families challenged the manner in which the center was closed – families were separated from their relatives by 20-30 state police as the remaining 49 residents were loaded into vans and transported to places unknown to them or their families. About a month after this incident, and in response to 30 complaints filed by family members, the Executive Director of P&A insisted that "the behavior of Office of Mental Retardation and center staff during those three days was exemplary" (Source: *OMR Planning Advisory Committee Meeting Summary*, May 22, 2000).
- ❖ In **Maryland**, P&A testified before the state legislature that "No one should have to live in an institution . . . The model of warehousing people with developmental disabilities in institutions is an outdated relic of history" (February 16, 2006). At this same hearing, family members and guardians testified in support of facility care for those who need specialized supports.
- ❖ In **Texas**, P&A intervened in the Lelsz lawsuit. Families spent over \$500,000 and intervened in the Lelsz lawsuit in attempt to preserve choice. Following the lawsuit, legislative action led to the closures of Travis and Fort Worth State Schools in 1995 and 1996
- ❖ In **Utah**, in response to a P&A lawsuit settlement, families retained legal counsel to prevent community placements of their family members, counter to choice and need. Despite assurances by P&A that these residents will not move, P&A recently renewed its call for the developmental center's closure.

Examples of state P&A's using their federal funds to eliminate the ICF/MR option, through legal and legislative means, are abundant. The need for immediate reform is clear.

**IV. REFORM PROPOSALS FOR THE REAUTHORIZATION OF THE DEVELOPMENTAL DISABILITIES ASSISTANCE AND BILL OF RIGHTS ACT**

VOR submits the following reform proposals to redress the problems of DD Act funding recipients not complying with the purposes of the Act, most specifically with the provisions supporting choice in residential settings and family decisionmaking. Reform is needed because the result of P&A litigation has often been the elimination of the public safety net for the nation's most vulnerable persons with developmental disabilities. The reform proposals are designed to assure that the purposes of the Act are carried out.

**For more information, please contact:**

**Mary McTernan**

President  
201 Brooksby Village Dr.  
#508  
Peabody, MA 01960  
978-535-2472 phone  
978-535-0472 fax

**Peter Kinzler**

Legislative Volunteer  
Consultant  
7310 Stafford Rd.  
Alexandria, VA 22307  
703-660-6415 home  
703-660-0799 office ph/fx  
[pkinzler@cox.net](mailto:pkinzler@cox.net)

**Larry Innis**

Washington  
Representative  
529 Bay Dale Court  
Arnold, Maryland 21012  
410-757-1867 ph/fx  
[LarryInnis@aol.com](mailto:LarryInnis@aol.com)

**Tamie Hopp**

Director, VOR Government  
Relations and Advocacy  
5005 Newport Dr., Ste 108  
Rolling Meadows, IL 60008  
605-399-1624 direct  
605-399-1631 fax  
[Tamie327@hotmail.com](mailto:Tamie327@hotmail.com)

VOR recommends that the DD Act be amended to require:

- A.** A freeze on P&A funding levels to give Congress time to review the programs and consider reforms.
- B.** A freeze on the use of funds for class action lawsuits involving the residents of ICFs/MR or, in the alternative, include language in the DD Act to further or strengthen Congressional intent by:
  - i.** Requiring that no P&A lawsuit may be filed against a CMS-certified facility that is in compliance with CMS regulations. If a facility is out of compliance, all CMS remedies must be exhausted before a P&A lawsuit can be filed.
  - ii.** Requiring that P&A's consult with, and obtain agreement from all the residents of an ICF/MR it seeks to represent, or, where appropriate, their families or guardians, before filing any type of lawsuit on behalf of those residents.
- C.** An HHS audit of how DD Act programs are working and whether they are respecting family choice and the *Olmstead* decision, to be submitted to relevant House and Senate committees within one year.
- D.** A three year reauthorization so that the Congress can more closely monitor how the DD Act is working and how HHS is implementing it.

VOR also calls on Congress to require that CMS conduct a study of whether states are offering people freedom of choice between an ICF/MR and HCBS waiver settings, as required by Medicaid law and regulation (*see*, 42 U.S.C. §1396n(c)(2)(C), 42 C.F.R. §441.302, and 42 C.F.R. §441.303(d)). Such study should be submitted to relevant House and Senate Committees within one year.

**CONCLUSION**

Thank you for your thoughtful review and compassionate support of VOR's concerns and recommendations for changes to the DD Act. Remember, Americans who can't help themselves because of no fault of their own are dependent upon the goodwill of Congress.

