VOR
Speaking Out for People with Mental Retardation

The Reauthorization of the Developmental Disabilities Assistance and Bill of Rights Act

The Need for Immediate Reforms

Robin Sims, VOR President
Rev. April 2010

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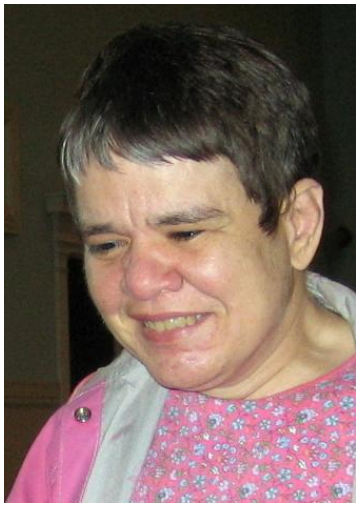
A Message from VOR's Immediate Past President



My 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 the Immediate Past 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 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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Rev. April 2010

Executive Summary

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

For the first time in ten years, Congress will be considering 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 and individual decisionmaking, some DD Act programs, through legislative lobbying, class action lawsuits and other tactics, 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. Protection & Advocacy (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 developmental disabilities, 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. Level fund DD Act program funding to give Congress time to review the programs and consider reforms.

B. Pass H.R. 1255 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. Secure an HHS audit of how all DD Act programs are working and whether they are respecting family choice and the *Olmstead* Supreme Court decision, to be submitted to relevant House and Senate committees within one year.

D. Limit the reauthorization to three years so that the Congress can more closely monitor the effectiveness of DD Act policy and DD Act program 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: VOR is a national organization advocating for the right of individuals with intellectual and developmental disabilities 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, Director of Government Relations and Advocacy at 605-399-1624 (direct); or Tamie327@hotmail.com.

Table of Contents

For More Information

Developmental Disabilities Assistance and Bill of Rights Act (DD Act): →
http://www.acf.hhs.gov/programs/add/adddocs/act.pdf

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

For a summary of the full Task Force Report, see,
http://www.vor.net/images/stories/pdf/DDActAbuseReport.doc

The full Task Force Report is here:
http://www.vor.net/images/stories/pdf/TaskForceReport.doc.

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

The Need for Immediate Reforms

I. INTRODUCTION

For the first time in ten years, Congress will be considering 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.

So far, a volunteer VOR task force has identified over 90 examples in 20 states of the DD Act programs' disregard for Congressional intent, often with tragic consequences to the displaced individuals.

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 2010 DD Act reauthorization (*see* page 12).

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

VOR Position – Our Family Members: People with Severe and Profound Mental Retardation: → http://vor.net/images/MedicaidMR.doc

Characteristics of Residents of Large Facilities: → http://rtc.umn.edu/docs/risp2008.pdf (pages 33-39)

Since 2000, the House Energy and Commerce Committee's membership has changed by at least 51%; the Senate Health Education Labor and Pensions Committee has changed by at least 57%. Reauthorization in 2010 provides an opportunity for the reconstituted Senate and House committees to scrutinize 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. 12) 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. 74.5% 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, 6,381 ICFs/MR are home to 93,164 people.

For More Information

Background and Milestones –ICFs/MR:
http://www.cms.hhs.gov/CertificationandComplianc/downloads/ICFMR_Background.pdf →

ICFs/MR: Meeting the Long Term Care Needs and Maximizing the Potential of Individuals with MR/DD:
http://www.ihca.com/consumer/ddcare.htm#Meeting

Characteristics of Residents of Large Facilities: →
http://rtc.umn.edu/docs/risp2008.pdf (pages 33-39)

ICFs/MR as Permanent Homes: →
http://vor.net/images/stories/ICFsMR_are_home.pdf

An invitation to visit an ICF/MR:
http://vor.net/images/ICFTour.doc →

Northern Virginia Training Center: →
http://www.nvtc.dmhmrsas.virginia.gov/

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.acf.hhs.gov/programs/add/adddocs/act.pdf

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.

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)).

For More Information

Olmstead decision resources: →
http://www.vor.net/olmstead_resources.htm

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

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

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

Visit 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

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).

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).

For More Information

To read Judge Payne's decision in Arc of Virginia v. Kaine, see, http://www.vor.net/images/SEVTCDecision.pdf

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)

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

Very recently, a U.S. District Court Judge for the Eastern District of Virginia cited "personal choice" as key principle in the Olmstead decision. In Arc of Virginia v. Kaine, the Virginia Office for Protection & Advocacy (VOPA), claimed that renovations to a state-operated ICFs/MR violated Olmstead because rebuilding and resizing the facility could force the plaintiff's members to be served at the renovated facility. Judge Robert Payne dismissed the lawsuit finding that plaintiffs failed to establish a "case or controversy" ripe for judicial review and, thus, the court lacked jurisdiction to hear the case. Recognizing that deinstitutionalization was the plaintiff's central motivation in this case, Judge Payne cited Olmstead, stating:

> Thus, the argument made by Arc [*represented by P&A*] and the United States [*Amicus in support of plaintiffs*] who filed regarding the risk of institutionalization fails to account for a key principle in the Olmstead decision: personal choice. And here, where more residents desire to remain in institutional care than the new facility can provide for, there is little to no risk of institutionalization for those whose needs do not require it and who do not desire it." (citation omitted)

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).

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).

ABUSE AND NEGLECT IN COMMUNITY SETTINGS: RESOURCES

VOR's Abuse and Neglect document: http://vor.net/abuse_neglect.htm (rev. March 2010)

Closing the Gap: A National Blueprint to Improve the Health of Persons with Mental Retardation, U.S. Surgeon General (2002): http://www.surgeongeneral.gov/topics/mentalretardation/

Bibliography of 72 peer reviewed studies about the abuse of children with developmental disabilities (2001): http://www.cfrc.illinois.edu/biblio.pdfs/abuseofdisabled.pdf

Special Olympics Health Research: Research studies conducted by Special Olympics found disturbing evidence that individuals with ID face widespread health problems, while health professionals are not receiving adequate training in order to treat them: http://vor.net/images/SOHealth.pdf

Quality Oversight Compared: A comparison between ICFs/MR and HCBS Waivers (2004): http://vor.net/images/ICFvHCBSQuality.doc

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

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 at least 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." 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.

PROTECTION & ADVOCACY LAWSUITS

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

DD Act, 42 U.S.C. 15041 and 15043(a)(2)(A):
http://www.acf.hhs.gov/programs/add/adddocs/act.pdf

P&A Class action lawsuits against ICFs/MR:
http://vor.net/images/PAClassActions.doc

Protection and Advocacy Agencies: Involvement in Deinstitutionalization Lawsuits, GAO-03-1044:
http://www.gao.gov/new.items/d031044.pdf

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.acf.hhs.gov/programs/add/adddocs/act.pdf).

P&A funding since the last reauthorization

P&A Funding, FY 2000 – FY 2010 (in millions)

2000	2001	2002	2003	2004	2005	2006	2007	2008	2009	2010
$28.11	$33.0	$32.34	$36.263	$38.416	$38.107	$37.928	TBD	$39.024	$40.0	$41.0

Class action lawsuits: HHS v. HHS

Since the late-1970s, there have been at least 30 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, at least nine such lawsuits have been filed. In the last five years (since 2005), there have been four lawsuits filed. At least seven lawsuits are pending, either as active cases or with court oversight of a settlement agreement. 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!

For More Information

VOR's Abuse and Neglect document: → 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. 15001(c)(3): http://www.acf.hhs.gov/programs/add/adddocs/act.pdf

Family testimonials → from **California**, **Kentucky**, **Ohio**, **Florida**, **Illinois**, **Arkansas**, **Pennsylvania**, **Maryland**, and **Utah** 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://www.vor.net/legislative-voice/additional-dd-act-reauthorization-resources/summary-of-family-testimonials

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*).

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.

For More Information

Family testimonials from **California**, **Kentucky**, **Ohio**, **Florida**, **Illinois**, **Arkansas**, **Pennsylvania**, **Maryland**, and **Utah** 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://www.vor.net/legislative-voice/additional-dd-act-reauthorization-resources/summary-of-family-testimonials.

- 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 filed a lawsuit to oppose a settlement agreement between P&A and the State that called 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."

- In **Illinois** in 2010, family guardians, on behalf of their family members, successfully sought intervention after several years of trying in a P&A lawsuit that threatens the closure of private ICFs/MR with more than 9 beds. Illinois' P&A agency has opposed efforts by families to intervene. In July 2009, more than 2,000 objectors, mostly families, successfully blocked a proposed settlement advanced by P&A and the State.

For more Information

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- 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 state operated facilities are seeking to intervene in a lawsuit filed by P&A that alleges all facility residents can and should be served in community settings. Families object to the lawsuits allegations and objectives and are seeking to intervene.

- 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 has 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.

For more Information

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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 DD Act program abuse has often been the elimination of the public safety net for the nation's most vulnerable persons with developmental disabilities: ICFs/MR. The reform proposals are designed to assure that the purposes of the Act's mandate to respect choice in residential settings and family decisionmaking is carried out.

VOR urges Congress to amend the DD Act as followed:

A. Level fund DD Act program funding to give Congress time to review the programs and consider reforms.

B. Pass H.R. 1255 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. Secure an HHS audit of how all DD Act programs are working and whether they are respecting family choice and the *Olmstead* Supreme Court decision, to be submitted to relevant House and Senate committees within one year.

D. Limit the reauthorization to three years so that the Congress can more closely monitor the effectiveness of DD Act policy and DD Act program 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)).

V. 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.

End.
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