

Winter 2007

NOTICE:
New VOR address
effective Aug. 1
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President's Message

Personal visits, says Rep. Barney Frank, are needed to get H.R. 3995 passed



By Mary McTernan
President

This afternoon I met with Rep. Barney Frank in his District office here in Massachusetts.

I am thrilled to report that in spite of the tremendous opposition from certain "advocacy" groups, he remains true to the principle that individuals and/or their families must be given notice before any federally-funded suit is filed against the facility where their severely mentally retarded family members live, and have a say in whether the individual should be included in the lawsuit.

"Who in this country gets sued in a court without formal notice" and no opportunity to "opt out?" he asks.

What more can we do to get H.R. 3995 passed?

My purpose in meeting with the Congressman during the Thanksgiving recess was to ask, "What more should I and VOR be doing to get H.R. 3995 passed?"

Rep. Frank responded to my question saying, "Now people must go and talk to their Congressman and/or some high ranking aide. You and I have done all we can do. Asking me 'what more should I be doing' is like having

your house on fire, the firemen there with the hoses on, and you calling me and asking, 'What more can I do?' The rest is up to your members. **Each person must convince his/her own Congressman.** Anyone can get an appointment. You didn't know me very well when you first started talking to me about this. Others have to talk to their Congressman/woman. That's it!!"

An appointment opportunity!

Until mid-January, members of Congress will be working in their district offices. **Now** is the perfect opportunity for you to **request an appointment** in late-Dec/early Jan. with your Representative. If you don't know who that is, or need help finding contact information for the district office near you, contact VOR's Director of Government Relations, Tamie Hopp at 605-399-1624 or Tamie327@hotmail.com. You can also find District contact information at <http://www.congress.org>.

To find contact information for your U.S. Representative:

Visit <http://www.congress.org> and enter your zip code

OR

Contact Tamie at 605-399-1624; Tamie327@hotmail.com

As Rep. Frank says, to take our advocacy to the next level, constituents in support of H.R. 3995 must **meet face-to-face with** their U.S. Representative. By far the most effective road to co-sponsorship is a personal visit.

Thank you very, very much for doing all you can do, especially your personal visits during the upcoming Congressional recess, to increase the number of H.R. 3995 cosponsors and **get H.R. 3995 passed.**

Together we will succeed!



Why seek a waiver?

In a nutshell, Medicaid Waivers provide the support individuals with significant disabilities need to live in the communities of their choice. These supports include Personal Care services and training services that support the individual in learning functional community activities. In many state waivers, Respite is a service offered that provides relief to the family. DM

Ensuring quality of life

As Danny's mom, my goal was to ensure Danny received quality of life in all areas of living. In doing so, it was important that Danny had an opportunity to reach his full potential. Quality of life for all children begins with a loving caring family.

Quality of life for all children begins with a loving, caring family.

The government's understanding of the importance of the family unit is proven in the approval of the Medicaid Waiver. Now it is our job to ensure all families of children with disabilities are aware of these options and that each state develop their waivers according to the needs of the children and families it serves. DM

Medicaid Waivers —

Medicaid – It's not just about income

By Denise Mercado

EP Magazine

August 2007

As my husband and I manned our table for the promotion of my book, *They Created Us*, at the 2007 World of Possibilities Expo in Maryland, we met several parents of children with disabilities. Many of these parents brought their children with them, and many of their children had significant disabilities similar to our son, Danny. Despite the obvious significant need of the child, when asked if these parents were aware of the Medicaid Waiver for individuals with mental retardation and developmental disabilities (MR/DD), the responses ranged from a surprised question, "What is that?" to mumblings of a waiting list or age restrictions.

One family of a fifteen-year-old talked about excellent early intervention services until age three but no home supports since. Another family talked about the Waiver being available to children with disabilities but that Maryland families were not encouraged to apply and that the target population was adults with disabilities.

These responses were no different from what I hear on a regular basis in North Carolina. Our family is a retired military family and lived in many different states. After many military moves, we arrived at Ft. Bragg in North Carolina in 1991. At the time, our son, Danny, was nine-years-old. Despite our son's significant disabilities, no pediatrician, social worker, or school official introduced us to the Medicaid Waiver. This information was provided in 1993 by other families. Danny was eleven-years-old when we first learned about Waiver services. We spent the next two years fighting to get off the waiting list. Finally in 1995, Danny was approved for North Carolina Medicaid Waiver services. Since that time, I have embarked on a crusade to get the word out about the Medicaid Waivers that are available in every state for individuals with mental retardation and developmental disabilities.

The Thomson/Medstat statistics indicate over \$17 billion dollars spent by all states in FY 2005 for Medicaid Waivers, specific to community support of individuals with mental retardation and developmental disabilities. In addition, over

\$12 billion dollars were spent in FY 2005 on institutional settings for the same target population.

During the past 24 years as I fought diligently to obtain services for my son, Danny, I learned the following about Medicaid Waivers.

The Center for Medicare and Medicaid Services (CMS) in Baltimore is the approving entity for all state Medicaid Waivers. The purpose of the Medicaid Waivers is to allow states the option to waive certain Medicaid criteria in order to assist individuals with disabilities to remain in the communities of their choice. The **three requirements that may be waived** under federal law are: **Statewideness, Comparable Services, and Deeming of Income and Resources.**

The Social Security Act requires Medicaid services to be provided on a **statewide** basis. In other words, a state must offer all the components of its Medicaid State Plan to those who qualify for Medicaid services. A state cannot geographically discriminate and offer only Medicaid state plan services to those living in a particular area of the state. However, if the state develops a special project and would like to test the project in a particular area of the state, the state would submit the project information to CMS, requesting a waiver of "statewideness." If approved, the state would be allowed to implement the project utilizing Medicaid funds in a particular area of the state.

The Social Security Act requires a state to provide **comparable services** in amount, duration, and scope to all Medicaid recipients. However, this criterion can be waived if the state chooses to target a particular population. For example, the state Medicaid Plan may indicate a certain number of Personal Care hours per month for individuals who qualify for the service. However, if the state is approved by CMS to target a certain population, such as individuals with mental retardation and developmental disabilities, then the state can offer within that target population a higher number of Personal Care hours per month as needed on an individual basis if they choose to do so.

The most important Medicaid criterion that can be waived by a state is the **deeming of income and resources.** Medicaid rules require that the income and resources of a spouse/parent be considered in determining Medicaid eligibility

eligibility NOT just about income

for a person who resides with a spouse/parent. This "deeming" of income and resources is to the Medicaid recipient and may be waived to allow Medicaid eligibility under the waiver to be considered similar to the methods used for people who are residing in an intermediate care facility for individuals with mental retardation (ICF-MR). As indicated in the Thomson/Medstat statistics, over \$12 billion dollars were spent in FY 2005 on ICF-MR settings. When an individual enters an institutional setting, the income of the individual is all that is considered regardless of the age of the individual. A parent's income is not considered when a child is admitted to an ICF-MR facility. However, when a child applies for regular Medicaid state plan services, the parent's income must be considered. In most cases, it is the family income that disqualifies a child from receiving Medicaid services despite the significant disability of the child.

This dilemma was solved by a courageous woman, Julie Beckett, in the early 1980s.

As a result of viral encephalitis at six months of age, Julie's daughter, Katie, had extensive medical needs that resulted in a three-year tenure at a pediatric intensive care unit. The parents learned all that was required in Katie's day-to-day care and wanted to bring their daughter home. However, the Medicaid income rule prevented this from happening. After a long battle led by Julie and her family, the government created a new standard known as the home and community based waiver program, often called the Katie Beckett Waiver program. Under this waiver, children would remain eligible for Medicaid by waiving the income deemed to them by their parents, since that income could not or would not cover the cost of their care at home. The Katie Beckett Waiver focuses primarily on those children who require intense medical technology such as ventilators. The Medicaid Waiver for individuals with mental retardation and developmental disabilities is a spin off of the original Katie Beckett Waiver and does not require the individual to have medical technology needs.

When states waive the Deeming of Income and Resources criterion in their waivers, they open the Medicaid door for children with significant disabilities of middle class families. The waiving of this criterion is an option to states and is not available in every state.

In developing the Waiver, a state must be specific as to the population it will serve. This includes not only the disability involved, but the age of the individuals as well. The North Carolina MR/DD Waiver does not have an age limit. Yet again, I meet North Carolina families on a regular basis who are told by local officials that their child is too young to receive services or to

Despite our son's significant disabilities, no pediatrician, social worker, or school official introduced us to the Medicaid Waiver. This information was provided in 1993 by other families.

even be put on the waiting list. To ensure families do not become entrapped in the snares of "gossip law" I encourage all families to learn the phrase, "Can you show me in writing where this is so?"

An important resource for Medicaid Waiver information is the CMS Baltimore office. The contact information for the regional CMS offices can be obtained at the CMS Baltimore office and website. Each state has an individual appointed as the waiver point of contact. This state contact information can be acquired at the CMS regional office.

As families move through the maze to obtain services, it is important to realize that knowledge of the Medicaid Waiver will not be enough. The waiting list issue is a legislative issue and another wall in the maze that many families will face.

About the author: In 1982, Denise gave birth to her second son, Danny. At six months of age, Danny suffered a severe bout of meningitis. Danny was a 24 year survivor of meningitis. He died on February 7, 2007. Denise's role as a staunch advocate has uncovered numerous injustices. Denise and her husband, John, have established Team Daniel, LLC in honor of their son, Danny. For more information on Denise's book *They Created Us*, please visit the Team Daniel website at www.teamdaniel.info.

Information IS

Power!!!

...in most places, the waivers are the best-kept secret. Medicaid Waivers are not advertised; there are no fliers at pediatrician offices or public schools. When families finally receive information needed to access waiver services, they are faced with flow charts that do not flow. At times families feel like the rat at the beginning of a large maze in a scientific project, and they are trying desperately to obtain the cheese. It is no cliché that knowledge is power. It is in fact, the first step in obtaining services...The contact information for the CMS Waiver point of contact for North Carolina is programmed in my cell phone and email address book. I suggest all families of children with disabilities do the same in their respective states. Through this contact source, a copy of the state's Medicaid Waiver manual for individuals with mental retardation and developmental disabilities can be obtained. DM

Don't fall victim to "gossip law."

I meet North Carolina families on a regular basis who are told by local officials that their child is too young to receive services or to even be put on the waiting list. To ensure families do not become entrapped in the snares of "gossip law" I encourage all families to learn the phrase, "Can you show me in writing where this is so?" DM

**Your Advocacy
"To Do" List:**

1. **TODAY**, identify your U.S. Representative (Visit <http://www.congress.org>; call Tamie/VOR at 605-399-1624; OR contact your local library).
2. **TODAY**, find contact information for the nearest district office.
3. **TODAY**, call the district office and request an appointment.
4. **TODAY**, contact Tamie at Tamie327@hotmail.com or 605-399-1624 for H.R. 3995 handouts and help with questions.
5. **TODAY**, share this Call to Action with other advocates.
6. **MEET WITH YOUR REPRESENTATIVE**, and ask him/her to cosponsor H.R. 3995. After the meeting, be sure to send a thank you note.

IT'S UP TO YOU!!!

Congressmen/women want to meet with CONSTITUENTS — that's YOU! Thank you very, very much — and remember, VOR is here to help.

**H.R. 3995
Co-Sponsors to Date:**

- Boustany (R-LA)
- Capuano (D-MA)
- Etheridge (D-NC)
- Gonzales (D-TX)
- Larson (D-CT)
- Lynch (D-MA)
- McGovern (D-MA)
- Miller (D-NC)
- Moran (D-VA)
- Paul (R-TX)
- Platts (R-PA)
- Shays (R-CT)
- Shea-Porter (D-NH)
- Walberg (R-MI)
- Woolsey (D-CA)

**Many, many more
are needed!!**

the voice Winter 2007

*Protecting the interests of each resident
of ICFs/MR in class action lawsuits
on behalf of such residents*

Introduced on October 30, 2007 by Rep. Barney Frank (D-MA), the key provisions of H.R. 3995 are:

- The attorneys filing federally-financed lawsuits must give the targeted facility at least 90 days notice before filing the lawsuit.
- The facility, upon receiving notice, must provide notice to all residents and "if there is a legal representative of such resident, to such representative."
- The residents (or, if where there are legal representatives, those representatives) have 60 days after receiving notice from the facility to elect to not be a part of the lawsuit (opt out).

**VOR's Call to Action!
HELP GET CO-SPONSORS!!**

VOR sent mail and email alerts to thousands of families and other advocates. Recognizing the importance of lining up cosponsors as quickly as possible, many of you have responded to VOR's calls to action by writing or calling your U.S. Congressional Representative asking that he/she cosponsor H.R. 3995. A template letter and phone message are available on VOR's website at: (<http://www.vor.net>).

Much, much more remains to be done. As Rep. Barney Frank has confirmed, **PERSONAL VISITS** are absolutely necessary to secure H.R. 3995 cosponsors. Your representative has a district office near where you live. Review the "Advocacy To Do List" on this page and call TODAY to make an appointment with your U.S. Representative. Congress is now in recess and there will be additional opportunities this Spring. Some VOR members met with the representatives in the District in December, and other meetings are scheduled for January.

You are the expert!

You are the expert regarding your loved one's needs — not some attorney who has never even met your family member. The message is simple: "I support H.R. 3995 because if any federally-funded group, including Protection and Advocacy, ever decides to pursue a class action lawsuit on behalf of my family member with profound mental retardation, I want to be notified. I also want the right to decide whether or not to have my family member included in the lawsuit. These decisions are best left to individuals and their families/guardians, not federally-funded attorneys. That's just good common sense. Please show your support by co-sponsoring H.R. 3995."

VOR is here to help. We can help identify your Representative and find district office location and contact information. VOR has also developed a number of position papers to support the passage of H.R. 3995 that you can share with your representative. VOR will help in every way, but YOU as the CONSTITUENT, need to CALL, WRITE and MEET with your U.S. Representative. **THANK YOU!!!**

**More than 80 natl., state & local groups
call on Congress to pass H.R. 3995**

"H.R. 3995 is desperately needed and supported by families of ICF/MR residents. VOR wrote 85 organizations from 26 states in a letter to be sent to Congress calling for passage of H.R. 3995.

VOR circulated the letter and secured organizational support to illustrate to Congress the broad, national support for H.R. 3995. Organizations joining the letter represent families and advocates for persons with mental retardation, support professionals, and other groups who support the principle that individuals and their families are the primary decision makers regarding the services and supports.

"H.R. 3995 is opposed by the lawyers who bring these suits, as it would limit their discretion with regard to who they are allowed to represent. The undersigned organizations, however, submit that the decision regarding attorney representation should be made by individuals and their legal guardians, not by attorneys," state these groups in their letter to Congress.

VOR continues to collect signatures. If your organization would like to be included on this joint letter to Congress, contact Tamie at 605-399-1624; or Tamie327@hotmail.com.

H.R. 3025 (Section 202) and S. 1107 – eliminating Rx co-pays

H.R. 3025 (Section 202), introduced by Rep. Lloyd Doggett (D-TX), and S. 1107, introduced by Senator Gordon Smith (R-OR) call for the elimination of Medicare prescription drug co-pay obligations for certain dual eligible (Medicare/Medicaid) individuals, including MR/DD residents of Medicaid Home and Community Based Services waiver group homes.

Pursuant to the Medicare Prescription Drug, Improvement and Modernization Act of 2003 (MMA), dual eligibles in “long term care facilities” are exempt from co-payments. Following MMA’s passage, the Centers for Medicare & Medicaid Services (CMS) published proposed regulations and expressly called for comments relating to the definition of “long term care facilities.” Recognizing that, “It is particularly important to ensure that the drug needs of institutionalized Part D enrollees – most of whom are dually eligible for Medicare and Medicaid – are met” and that “[t]he institutionalized population is generally more sensitive to and less tolerant of many medications,” CMS sought to determine from advocates whether ICFs/MR should be included in the definition of “long term care facilities.”

VOR’s comments strongly encouraged CMS to include ICFs/MR in the definition of “long term care facilities” so that ICF/MR residents would be exempt from co-pay obligations. Further, VOR noted,

on J. VOR also supports including individuals receiving home and community-based waiver supports in the definition of ‘institutionalized.’ Waiver placement eligibility criteria is identical to eligibility for ICF/MR placement. Due to ongoing, whole-sale efforts to serve almost all of the ICF/MR-eligible population in less restrictive waiver settings, it seems misguided and even dangerous to transfer or divert these individuals from ICF/MR supports and then also restrict their prescription medication options simply because of where they are now living.”

ICF/MR residents were granted an exemption from co-pay obligations, but waiver recipients were not. H.R. 3025 and S. 1107 aim to address this inequity.

Bill would require background checks

H.R. 3078 and S. 1577 expands the three-year pilot program to examine ways in which states can implement systems to cost-effectively screen applicants for employment in long-term care facilities. The bill requires national and state screening, in-

cluding national criminal history background checks, of direct care employees of long-term care facilities including ICFs/MR, and prohibits the hiring of abusive workers. The bill would require that such background checks be reimbursed by Medicare and/or Medicaid programs. (Source: *Perspectives*, NASDDDS, Nov. ‘07; see www.nasddds.org, for subscription information).

Congress proposes moratorium on Medicaid rules

The Bush administration has proposed far-reaching Medicaid changes one at a time since the start of the year, saying they are essential to curb abuses in Medicaid. The proposals, which would make it harder for tens of thousands of Medicaid beneficiaries to access services have drawn sharp criticism from Congress, governors. The proposals, opponents claim, could force some states to restrict some services or pick up more of the cost.

Although the administration can impose regulations without Congressional approval, Republicans and Democrats in Congress are fighting the changes. Congress has temporarily blocked two of the changes, imposing a moratorium until May 2008 on cutting doctor-training money and limiting state funding options. The new State Children’s Health Insurance Program (SCHIP) bill, revised after being vetoed by the President in early October, contains provisions to prohibit until January 1, 2010, action to restrict coverage or payment for Medicaid rehabilitation services, or school-based administration, transportation, or medical services that would be more restrictive than those existing as of July 1, 2007. If vetoed again, some in Congress are looking to include this moratorium in a more “veto proof” bill. (Source: *Boston Globe*, Nov. 13, 2007; and Center for Workers with Disabilities, October 2007).

HCBS recipients more likely to live with parents/ other relatives

A new study shows that the number of people with mental retardation receiving Medicaid Home and Community Based Services (HCBS) while living with family members is an estimated 224,264 individuals as of June 20, 2006, 17 times higher than in June 1999. A notable policy trend that corresponds with this increased reliance on family-based living, is the growth of Medicaid Support Waiver programs. HCBS Supports Waivers limit total expenditures to amounts that are typically considerably less on average than is provided in the regular HCBS program, in exchange for greater flexibility (Source: Intellectual and Developmental Disabilities, AAIDD, October 2007).

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Legislative Briefs

A Special Tribute and Thank You to Long Time Leader, Louise Underwood

Recently, Louise Underwood, VOR’s co-founder, a retired board member, and past chairperson of VOR’s legislative committee, resigned from VOR’s legislative committee. Indicating that the time was right for her to step down from this committee assignment she stated, “I will continue to do everything I can for VOR.” She notes that VOR’s role has been (and remains) to “Help change laws that will help families to give their family member a decent quality of life and be given the CHOICE to where they receive those services. VOR is the hope for the future for our people.”

Louise embodies the spirit of generosity and volunteerism.

As she says, “we must all stand together . . . UNITED WE ARE STRONG – DIVIDED WE ARE WEAK.”

All of us in VOR are indebted to Louise for her many years of service to VOR. Her contributions in advocacy and leadership over the past 25 years are priceless. Many, many doors in Washington, D.C. are held wide open for VOR representatives because Louise paved the way. She’s a leader, a trailblazer, and an effective advocate on behalf of people with mental retardation in Kentucky and around the country. For all you have done for VOR, and will continue to do, thank you, Louise!

**California:
State/Families Appeal
Class Certification Ruling**

In the last issue of *The Voice*, we reported that a state appellate court had reserved the trial court's ruling denying California Protection and Advocacy's (P&A) request for class certification.

This disappointing ruling meant that the case, *Capitol People First v. Department of Developmental Services*, would proceed as a class action lawsuit on behalf of more than 7,000 individuals who are either living in state or private facilities, or are at risk of institutionalization. State defendants and interveners (the families of facility residents)

VOR has joined with the state defendants and interveners, filing a letter with the Superior Court, urging it to review this important case and deny class certification.

oppose class certification, arguing that because everyone's needs are individual, issues over inappropriate institutionalization can only be addressed on an individual, case-by-case basis.

They also argued that P&A could not represent the interests of the class, given its express bias against the facility option.

In early November, the State and family interveners filed its notice of appeal, in an attempt to reinstate the original order denying class certification.

The request is before the California Superior Court, the highest state court, which will decide within 60 days whether or not to accept the appeal.

**Maryland: Mentally disabled
can challenge placement denial**

State and U.S. Constitutional due process rights require that an individual denied admission to a state operated ICF/MR have the opportunity to appeal that decision. Because the state statute does not provide for any opportunity for appeal, it is unconstitutional, a state court held recently.

Mary Reese, stepmother and guardian to Virginia Massa, has been seeking admission for Virginia at Holly Center, a state operated center in Salisbury, MD. She sued after failed attempts to have evidence regarding Virginia's eligibility and need for Holly Center care considered at the administrative level.

Although this court ruling does not guarantee Virginia's admission, it does ensure that Mary and Virginia and other individuals and their guardians will have their day in court.

VOR has been watching this case carefully, having identified its potential for far reaching change in the way Maryland considers admissions to the state's 4 centers. For this reason, VOR helped arrange

for attorney representation. Dan Rabinowitz, an attorney for Sidley Austin, has done a remarkable job of representing his clients in this case, and Nirali Patel before him. VOR is very, very grateful for their assistance in this legal matter.

Although this court ruling does not guarantee Virginia's admission, it does ensure that Mary and Virginia and other individuals and their guardians will have their day in court.

**California: Conservator wins
an important case on behalf
of the developmentally disabled**

A recent California state appellate court held that conservators and other authorized representatives of the developmentally disabled have a statutorily protected role in the planning for treatment and placement decisions. As a result of the decision, conservators and other authorized representatives of the developmentally disabled will be better able to secure the legislatively mandated level of appropriate care, which has all too frequently been overlooked in the rush to "de-institutionalize" this vulnerable population.

**Delaware: Court determines state
can't violate woman's right to travel**

U.S. District Court Judge Gregory Sleet said September 11 that the State of Delaware not processing and approving a Medicaid application on behalf of a North Carolina resident with DD until she moves to Delaware is a "violation of her constitutional right to travel."

The 33-year-old woman, whose disabilities include autism, intellectual disability, blindness, and seizures, is a Medicaid beneficiary and currently resides in an intermediate care facility for mental retardation (ICF/MR) in North Carolina.

Her parents, who cannot care for her on their own, according to the court document, moved to Delaware in 2001 and began application to the Delaware Division of Developmental Disabilities Services (DDDS) for residential placement and services for their daughter through the state's Medicaid Program.

When DDDS "determined that [the woman] was not a (Delaware) resident and her residential placement needs were not 'urgent'....[and therefore she] would not be provided with community residential services," her parents filed a lawsuit on her behalf in 2005.

Judge Sleet, in his September 11 decision in *Duffy v. Meconi et al*, denied the state's motion for summary judgment and granted the plaintiff's motion for summary judgment. Delaware state officials, according to an Associated Press report, said they will appeal the ruling. Source: *Community Services Reporter*, NASDDDS, Nov. 2007; see www.nasddds.org, for subscription information.

**West Virginia: Class action case
seeks benefits**

Shawn Shumbera, a 27-year-old West Virginian with developmental and other disabilities who has resided in the Mildred Mitchell-Bateman Hospital since 2001, filed a class action lawsuit August 24 against West Virginia Department of Health and Human Resources Secretary Martha Walker for being denied a Medicaid home and community-based waiver for services.

Mr. Shumbera seeks MR/DD program benefits for himself and any member of the class. Source: *Community Services Reporter*, NASDDDS, Nov. 2007; see www.nasddds.org, for subscription information.

Pennsylvania: Notification required for removal from program

Two individuals with intellectual disability living in personal care homes in Scranton, Pennsylvania filed a lawsuit November 5 against the state's Department of Public Welfare (DPW) claiming it removed them and others off a benefit program without proper notification or the right to appeal.

According to the complaint, filed by Robert Meek of the Disability Rights Network of Pennsylvania, DPW in January 2007 informed plaintiffs and about 75 other Pennsylvanians living in personal care homes who were receiving services through the Consolidated Waiver that their enrollment in the waiver was terminated and that they had no right to appeal. DPW had received federal approval December 2006 to amend its Consolidated Waiver to exclude from eligibility all individuals residing in personal care homes.

DPW transferred plaintiffs to another home and community-based waiver program "that confers a far more limited entitlement to services than the Consolidated Waiver," the complaint says. Plaintiffs, because of their intellectual disability, did not understand the notice DPW sent them or its consequences. Another allegation, the complaint says, is that DPW did not afford plaintiffs and others any assistance in finding alternative housing. Plaintiffs are seeking declaratory and injunctive relief. Source: *Community Services Reporter*, NASDDDS, Nov. 2007; see www.nasddds.org, for subscription information.

Colorado: Arbiter issues award to parents of autistic girl

An Arbiter issued an award November 20 to parents of a young girl with autism who had filed a lawsuit against Anthem Blue Cross and Blue Shield to cover applied behavior analysis (ABA) autism therapy for their daughter. The award includes the coverage of ABA therapy under the

Anthem PPO Policy; reimbursement to the parents for costs in pursuing and prosecuting the arbitration; and the commitment of the Counsel to meet within 30 days to resolve other remaining issues in the case.

"We undertook this battle with two goals," explained Jill Tappert, mother of four-year-old Abby. "(1) To get coverage for Abby's treatment and (2) To help the rest of the autism community by setting a precedent and, win or lose, by educating as many people as possible along the way." Source: *Community Services Reporter*, NASDDDS, Nov. 2007; see www.nasddds.org, for subscription information.

New Jersey: State ins. must cover autism services

New Jersey's Supreme Court upheld an appeals court ruling September 12 to order the state's health insurance plan to cover autism services such as speech therapy, occupational therapy, and applied behavioral analysis/verbal behavior therapy for children of state government workers.

The January 17, 2007 appeals court ruling in *Micheletti v State Health Benefits Commission* said, "In this case the denial of coverage for [Jake Micheletti's] prescribed treatment is couched in terms of the contractual exclusion of benefits for non-restorative speech, physical and occupational therapy, but the medical evaluations of Jake indicate that the therapy is the only treatment modality for an autistic child. Denial of the treatment amounts to exclusion from coverage of a class of dependents, notably afflicted children, based on the nature of their mental illness, which is beyond the limits of the statutory authority of the [State Health Benefits Commission].... We hold the exclusions relied upon by the SHBC to deny coverage for the treatment sought for autism are void. We direct that speech and occupational therapy be instituted for Jake without delay, and that the date of coverage is retroactive to the date of the initial petition." Source: *Community Services Reporter*, NASDDDS, Nov. 2007; see www.nasddds.org, for subscription information.

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North Carolina: 4th Circ. hands down positive Medicaid/1983 ruling

Summary: In "Doe v. Kidd" the fourth circuit upheld the right to sue in federal court when the State fails to provide Medicaid services with "reasonable promptness." This is a major victory for families who need Medicaid residential MR/RD services.

The Fourth Circuit in *Doe v. Kidd* that Medicaid – which guarantees provision of medical assistance with "reasonable promptness" – is privately enforceable – meaning individuals have a right to sue if a state fails to provide services for which they are eligible. The Court did not rule whether an individual can sue claiming failure to enforce the Medicaid's freedom of choice provi-

This is a major victory for families who need Medicaid residential MR/RD services.

sion because it held that the plaintiff had failed to state a claim for its violation.

In this federal case, Doe, a developmentally disabled adult sought a waiver for community-based care from South Carolina but only received respite care. After waiting several months and exhausting administrative appeals, Doe sued South Carolina for failure to provide community-based residential care with "reasonable promptness."

Ohio:

State operated program approved

With his signature on the budget bill, Governor Strickland recently made history by agreeing to the creation of a pilot state-operated, residential program for individuals with mental retardation and developmental disabilities (MR/DD).

The state employees union, OCSEA, had aggressively pursued the creation of the pilot that will offer up to 10 residential waivers lots in group-like settings in the area of Gallipolis Developmental Center - all staffed by state employees.

"For the first time in history, Ohio will have a residential program that offers real

Having the state operate these beds will ensure even the hardest to serve are offered a community placement...

choice for individuals with severe mental retardation and developmental disabilities to live in group home-like settings," said MH/MR/OVH Assembly President Monty Blanton, who worked with key legislators to get the project off the ground.

In the budget testimony and elsewhere, OCSEA argued that individuals with severe needs do not have the choice to live in the community because private providers can choose not to serve them.

"Having the state operate these beds will ensure even the hardest to serve are offered a community placement, if they want it," Blanton said in testimony. Source: Public Employee Charter, OCSEA, Summer 2007

the voice Winter 2007

Oregon: State pledges better care for disabled

Gov. Ted Kulongoski in November called for swift reforms in the state's care system for people with developmental disabilities, and key Oregon lawmakers said they would make the issue a priority in February's special legislative session.

The push comes after The Oregonian reported that at least one of every five adult clients in state-licensed foster or group homes have been victims of serious abuse or neglect since 2000, the year the state closed its primary residential institution for the developmentally disabled, the Fairview Training Center in Salem.

"We are going to look into what's possible in terms of responding to the issues raised in the story," Kulongoski said in a statement. "The goal in moving people out of Fairview was to ensure they have better care, and we need to do everything we can to make sure that happens."

Advocacy groups also turned up the political heat, writing to lawmakers and demanding a meeting with state Department of Human Services officials to determine what can be done to reduce the frequency of abuse in the system.

The state cares for about 4,200 adults with conditions such as autism, mental retardation and cerebral palsy in 1,100 group and foster homes across the state. They are among 16,000 developmentally disabled Oregonians who receive various state services.

Oregon Department of Human Services Director Bruce Goldberg said that Kulongoski asked him to "accelerate our timeline" on putting together a computerized registry to identify abusive caregivers and deny them employment.

The state originally planned to study the issue and ask for funding at the next regular legislative session in 2009.

"We're going to be working with the Legislature to do that in February," Goldberg said.

Unlike more than half of all states, Oregon does not use a registry to track caregivers with a record of abuse or neglect.

More than 2,000 abused

The Oregonian found that in the seven years since Fairview closed, more than 2,000 developmentally disabled adults were victims of abuses ranging from neglect of medical needs to rape, beatings, thefts, verbal harassment and improper restraints.

At least 14 residents died after workers failed to provide necessary care.

The newspaper found that many workers in the system receive little training, are reluctant to call 9-1-1 in a medical emergency and get little oversight from overburdened caseworkers, who must manage clients and police the system at the same time.

In the vast majority of abuse and neglect cases, state-paid care providers were responsible.

The newspaper identified more than 200 caregivers who investigators found had committed more than one case of abuse. State officials said that had a caregiver registry been in place, 74 of them would have been barred from employment.

Stiffer penalties planned

In addition to speeding up the registry, Goldberg said the agency also plans to increase the fines and civil penalties for group and foster home operators who abuse or neglect clients.

Goldberg said his agency would support a bill -- not yet drafted -- to require the state to notify clients, their case managers and guardians once an abuse is substantiated in their group or foster home.

Nearly seven in 10 group home workers leave their jobs within the first year. The high turnover creates higher costs for recruiting and training replacements, and studies have shown it contributes to abuse. The average pay for a direct-care worker in Oregon is less than \$10 an hour.

It was not immediately clear whether the solution would include more money. The state now pays group and foster home providers about \$134 million a year.

Earlier this year, lawmakers approved a \$20 million increase primarily to boost caregiver

At least 14 residents died after workers failed to provide necessary care.

Oregon ...continued

wages. Providers had lobbied for three times that amount.

Advocates ready

Advocates for people with developmental disabilities this week positioned themselves to be part of any legislative action.

At an emotional meeting Tuesday, nearly two dozen members of the Oregon Developmental Disabilities Coalition, a statewide network of dis-

Nearly seven in 10 group home workers leave their jobs within the first year. The high turnover creates higher costs for recruiting and training replacements, and studies have shown it contributes to abuse.

ability groups, discussed what could be done to make the system safer.

The coalition later called for a special meeting with DHS officials "to basically to go over all of the systems issues that were raised" by The Oregonian's report, said Bill Lynch, who runs a federal and state-financed group, the Oregon Council on Developmental Disabilities, charged with advocating for people in the system.

Lynch said the persistence of abuse and neglect since Fairview closed is a wake-up call not only for state officials and lawmakers, but advocates as well.

"I just feel such a sense of personal failure," Lynch said. "We all need to own this problem." Judy Cunio, the Self Advocacy Coordinator for the Oregon Council on Developmental Disabilities, said the state needs to take action.

"I'm feeling very emotional," said Cunio, who suffers from cerebral palsy. "As a person with developmental disabilities, I've been around. I've seen and heard about people being mistreated. I've been mistreated myself. I think a lot of the mistreatment happens because people look at us and see an easy target." Source: *Oregonian*, November 10, 2007 (note this is part of a 4 day series - Nov. 4 - 10. See

<http://blog.oregonlive.com/oregonianextra/2007/11/grouphomes.html>).

**Washington, D.C.:
Promises, Promises:
The District has three months
to show it can help
developmentally disabled residents**

Saturday, September 15, 2007
Washington Post Editorial

The D.C. government has made a lot of big promises about improving the treatment of the mentally retarded men and women in its care. Over the years, it has broken most of those promises, and the result has been the neglect, mistreatment and even the deaths of many vulnerable people. Now a judge is demanding that the District keep some little promises. If it fails, it will be clear that the District is simply incapable of providing proper care, and the court should feel compelled to take over the system.

U.S. District Judge Ellen S. Huvelle, presiding over the 31-year-old class action lawsuit involving onetime residents of the notorious Forest Haven facility, has made no secret of her aggravation over the lack of progress in protecting the health and safety of developmentally disabled residents. Decrying "the tortured history" of the case, Judge Huvelle in March found D.C. officials in "systematic, continuous, and serious non-compliance with many of the court's orders."

Still, she has resisted placing the Department of Disability Services in receivership. This week, she issued an order that refreshingly focuses on tangible steps to improve the health and safety of the some 650 surviving members of the plaintiff class. The beauty of the judge's approach is that it compelled the city and the plaintiffs to come up with specific goals that can be accomplished in the next 90 days.

There's nothing pie in the sky about the list that Judge Huvelle accepted this week. It includes recruiting five providers of high-quality residential care, expanding a medical clinic program, figuring out which homes really are substandard, and identifying and treating the 25 most medically fragile residents.

Key to recruiting and retaining qualified providers is the District's promise to increase the rates it pays. Cost-of-living increases inexplicably were frozen for five years. That D.C. Mayor

Continued on page 10

**Kentucky:
Oakwood vastly improved
under new management**

By Donald Putnam

(Putnam of Lexington is president of the Parent-Relative Organization for Oakwood Facilities, and a member of VOR)

November 5, 2007

It has been a year since the Bluegrass Mental Health-Mental Retardation Board took over managing/operating Oakwood in Somerset.

Oakwood is home to 232 people with developmental disabilities. They are some of the most fragile and vulnerable of Kentucky's citizens. More than 1,000 skilled staff members provide care for them. It is challenging work.

Using many measures, Bluegrass has done a remarkable job. We are not where we want and need to be, but we are not where we once were, either.

While the state administration's Cabinet for Health and Family Services can take credit for accepting the Bluegrass offer to operate Oakwood, it also must take responsibility for the chaos and severely dysfunctional facility that existed for the previous three years.

In 2005, the Centers for Medicare and Medicaid Services decertified Oakwood and threatened to cut off 75 percent of Oakwood's funds. These funds have been temporarily restored pending a successful CMS survey.

In October 2006, a court monitor and five expert consultants visited Oakwood and found that except for two areas, there was a significant decline in the quality of services at the facility.

However, since Nov. 1, 2006, several significant accomplishments were realized. In April, the court monitor and five experts visited Oakwood and found significant gains in stabilizing the facility, improving staffing and morale and the quality of supports and services. The facility is preparing for this month's visits from CMS and the court monitor.

Medeiros background

Kristine Medeiros has mental retardation and autistic tendencies, and developed retinal detachment in one eye since moving to the Woburn home five years ago. Kristine is verbal and friendly, although she can self-injure when frustrated or confused. She can write notes to her parents and house staff describing what happens to her.

After a year of arguments with her parents about face guards and medication errors, Nexus notified DMR that it was canceling the contract regarding Kristine's services effective August 28, 2007 and would evict her from her home of 5½ years. Nexus and DMR gave no notice and no hearing as mandated by M.G.L. 123B, and the proposed new home, with lower-functioning (non-verbal) residents, does not meet Kristine's needs.

Chapter 123B Section 3 (<http://www.mass.gov/legis/laws/mgl/123b-3.htm>) guarantees that transfers of people with mental retardation require 45 days written notice to guardians, which notice has to include a statement of how the transfer "will result in improved services and quality of life for the retarded ward," and the right of guardian to "examine" the new facility. Individuals and guardians may appeal, and no transfer can be made while the appeal is in progress.

State News continued from page 9

DCcontinued...

Adrian M. Fenty (D) is agreeing to come up with the \$4.7 million city share (Medicaid and Medicare would pick up the rest of the \$15.6 million tab) is a hopeful sign of his administration's commitment to reform.

Make no mistake: If the District meets all the goals, there are still major problems in the system and much more to be done. The next three months will be a gauge of the city's ability to make changes, and the results will be known on Jan. 17. If D.C. officials can't keep their promises this time, we don't see how the judge has any other option but to place the system in receivership.

Legal News continued from page 7

Massachusetts: Private group homes must follow state law

In a decision likely to affect persons with developmental disabilities for years to come, Superior Court Judge Geraldine S. Hines issued a preliminary injunction Monday prohibiting the Massachusetts Department of Mental Retardation and Nexus, Inc. of Woburn from transferring Kristine Medeiros (See sidebar), 37, from her group home in Woburn without affording her the protections of M.G.L. 123B, the statute which regulates the movement of mentally retarded people from their homes. The judge specifically rejected the argument by DMR and Nexus attorneys that privately operated group homes under contract with DMR were not "facilities" regulated by Chapter 123B.

"This decision about one woman is an important precedent for the vast majority of the 32,000 people in Massachusetts with mental retardation/developmental disability," said COFAR President David J. Hart. "The judge has made it clear that privatizing the system of care for people with MR/DD does not undo the rule of law protecting mentally retarded

people served by the Commonwealth from being evicted from their homes. Private non-profits can't pretend that they are above the law."

The case is unrelated to, but has some parallels with, the federal court case about closing the Fernald Center, where Judge Joseph Tauro ruled August 14 that residents must be offered the option of remaining in their long-term home. The case has been appealed by DMR to the United States Court of Appeals. October 17, 2007 COFAR, <http://www.cofar.org/>

Legislative Briefs continued from page 5

New research considers the lessons learned from deinstitutionalizing mentally ill

In August, the Kaiser Commission on Medicaid and the Uninsured released a study that reviews the lessons learned from the mass deinstitutionalization of people with mental illness, beginning in the mid-50s. Noting that "overall progress was extremely slow and resources for community care were a major issue," the report concludes, "Unfortunately, deinstitutionalization and many other reforms are often too quickly followed by backsliding and public indifference, leading to a wide discrepancy between expectations and achievements...it is crucial that the lessons of the past be heeded." (Learning From History, August 2007).

Down syndrome legislation introduced

Senators Sam Brownback (R-KS) and Edward Kennedy (D-MA) have introduced S. 1810 Prenatally and Postnatally Diagnosed Conditions Awareness Act, which would provide \$5 million "to increase the provision of scientifically sound information and support services to patients receiving a positive test diagnosis for Down syndrome or other prenatally and postnatally diagnosed conditions." A companion bill, H.R. 3112, has been introduced in the House. (Source: *Perspectives*, NASDDDS, November 2007; see www.nasddds.org, for subscription information).

VOR Calendar Events

Families USA Health Action 2008,

National Grassroots Health Advocacy Conference

January 24-26, 2008 in Washington, D.C. VOR is a sponsor. See, <http://www.familiesusa.org/conference/health-action-2008/>, for more information.

VOR 2008 Annual Meeting and Initiative:

June 13 – 19, 2008 in Washington, D.C. An event to commemorate VOR's 25th Anniversary will be held on June 14.

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To receive the update directly, contact
Tamie327@hotmail.com

About VOR

VOR is a national non-profit, 501(c)(3), volunteer-based advocacy organization. VOR is dedicated to ensuring that individuals with mental retardation receive the care and support they require in quality settings appropriate to their needs.

Send articles to be considered for use in *The Voice*, or other VOR publications, to:
VOR, attn: Tamie Hopp
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as appropriate: _____ I am current member and my record needs updating (i.e., new address, name, phone, etc.). I have circled the changes needed on this form.
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If the minimum dues requirement poses a financial difficulty, please contact our office in confidence. It is in our best interest that you receive VOR's information, so please call if \$25 per year poses a financial hardship.

Dec07NL

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