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Media coverage highlighting the increasing need for more effective federal and state protections in the ever-expanding community system of care for people with mental retardation

Washington, D.C.
Associated Press, December 15, 2008
Woman at D.C. group home is homicide victim

Authorities say a woman's death at a group home in Northeast D.C. has been ruled a homicide. D.C. Council member Muriel Bowser says police responded about 4 p.m. Sunday at the home for the mentally disabled in the 5400 block of Blair Road NE. Bowser says the home is operated by a contractor, and she is unaware of any complaints about the home. Authorities have not revealed the cause of death. Police Inspector Rodney Parks said Sunday evening that the case had been closed. The District's care of its disabled citizens as been in question since December 1999 when reporter Katherine Boo's Pulitzer Prize winning investigative series, "Invisible Deaths: The Fatal Neglect of D.C.'s Retarded" (see below).

Washington, D.C.
Washington Post, October 22, 2008
Disabled Man Died Before Needed D.C. Aid Arrived

"Mr. Johnson" badly burned himself while trying to cook. There were roaches on him when he showed up for medical appointments. He had difficulty using the toilet and rarely took his medication. But for years, the 65-year-old was deemed ineligible for help by the District agency that cares for mentally and physically disabled residents. For bureaucratic reasons, he officially did not exist.

In February, the District finally approved funding for him. It was for his burial.

That detail made the District's acting attorney general, Peter Nickles, call it "a sad story, the ultimate sad story," and a case that "fell through the cracks." City officials yesterday acknowledged mishandling the case and vowed to investigate.

Mr. Johnson, the pseudonym used by lawyers who took up the man's case in recent years, was hit by a bus when he was a toddler, in the 1940s. Doctors concluded that he was left mentally disabled, and for decades he remained at home under his mother's care. When the mother died 15 years ago, the man's well-being fell to a volunteer who cleaned, shopped and tried to arrange medical care from the city's agency for the mentally disabled. But the volunteer's efforts could not keep the man from living in squalor, hurting himself, skipping his medication and ultimately dying in a diabetic coma.
The legal advocacy group said it wrote the report to shine a light on a bureaucracy's fatal focus on paperwork protocol that kept a person in need from getting help. "We have other clients like him who have been waiting around for services, and they are denied services simply because they don't have the right records, usually documents from D.C. public schools," said Mary Nell Clark, managing attorney for University Legal Services.

The group represents abuse victims in a 30-year-old lawsuit against the District over quality of care in group homes for the mentally and physically disabled.

Illinois
Associated Press, March 21, 2008
Disabled pregnant woman used as target practice

Banished to the basement, the 29-year-old mother with a childlike mind and another baby on the way had little more than a thin rug and a mattress to call her own on the chilly concrete floor. Dorothy Dixon ate what she could forage from the refrigerator upstairs, where housemates used her for target practice with BBs, burned her with a glue gun and doused her with scalding liquid that peeled away her skin. Her attackers / housemates included Michelle Riley, 35, who they said befriended Dixon but pocketed monthly Social Security checks she got because of her developmental delays, Judy Woods, three teenagers (including Riley's 16-year old daughter), and Riley's 12 year old son. They torched what few clothes she had, so she walked around naked. They often pummeled her with an aluminum bat or metal handle. Dixon -- six months pregnant -- died after weeks of abuse. Police have charged two adults, three teenagers and a 12-year-old boy with murder in the case that has repulsed many in this Mississippi River town. Riley and Dixon, police said, had lived in Quincy, a Mississippi River town about 100 miles north of St. Louis, Mo. Quincy is where Riley worked as a coordinator for a regional center that helps the developmentally disabled with housing and other services. Dixon was a client. "The idea that someone would say, 'Have the handicapped people do it' is very disturbing," he said. "They just cut the grass and do the weeding. They work so hard."

Washington, D.C
Washington Post (column), March 16, 2008
Putting Mentally Disabled at Risk Is No Way to Cut Corners

Demolishing a building that dates back to the days of asbestos is a complicated business. You need to examine the construction method and, often, call in the men in white suits. When the Federal Aviation Administration decided to knock down an old guard shack last year on the grounds of the Washington Air Route Traffic Control Center in Leesburg, no such precautions were taken. Instead, managers called in a crew of mentally disabled people and put them to work at the site, which had been found in 1993 to contain asbestos. Now, the FAA says, the agency's inspector general, federal prosecutors in Alexandria and a grand jury are investigating whether the decision to give part of the job to people with severe disabilities was a purposeful attempt to circumvent procedures. A crew of about half a dozen workers from Echo Inc. (Every Citizen Has Opportunities), a Leesburg-based charity that trains and provides jobs for mentally retarded and other disabled people in Loudoun and Fairfax counties, has handled groundskeeping duties at the FAA facility for three decades, Echo Executive Director William Haney said. Haney said that when he heard about the asbestos incident, he asked the FAA for a written report on what role his workers had played but "never got anything." Haney was told that the workers' role in the demolition was "incidental," but, he said, "I just don't know what went on."

South Carolina
The Item, March 9, 2008
DSN under the microscope

Allegations of abuse, financial fraud have cast a shadow over a county agency whose clients are among the most "fragile and vulnerable." The director of the Sumter County Disabilities and Special Needs Board has been removed from his position and charged with five counts of criminal sexual conduct and two counts of kidnapping. He and the local board are defendants in a lawsuit brought by former employees alleging a hostile work environment and improper termination. In an unrelated incident, an employee of the Sumter County DSN Board has been charged with breach of trust with fraudulent intent after allegedly bilking the organization of

$75,000. Whether coincidental or systemic, the nature and number of charges connected to the special needs agency are significant enough to warrant a closer look.

Even before the most recent charges, a group of lawmakers had decided there was sufficient cause to seek an audit of the entire department by the Legislative Audit Council. The state audit is expected to be finalized later this year.

The state Department of Disabilities and Special Needs serves those residents who have development disabilities, autism, head or spinal cord injuries or mental retardation. The state department, which opened in 1967 as the Department of Mental Retardation, acts as an umbrella to 39 local disabilities and special needs boards that serve the state's 46 counties, including Sumter County. The Sumter County board employs about 275 full- and part-time workers and serves about 600 clients. The board provides a variety of services, such as early intervention to help families assess children from birth to age 6; individualized rehabilitation to help clients have greater independence; helping clients find jobs; supervised living for adults able to live on their own; and community training homes for those who need a little more assistance. The board also hosts camps during the summer months. The Sumter agency was established by state law and county ordinances and is governed by a seven-member board, whose members are appointed by the governor upon recommendation of the local legislative delegation.

North Carolina
News & Observer, February 24 – March 2, 2008
Mental Disorder: The Failure of Reform

The series focuses on the aftermath of the 2001 mental health reform including aggressive deinstitutionalization, including findings of extensive financial fraud, astronomical community costs, and compromised treatment. It was predictable – people were displaced from psychiatric hospitals before community services were in place, costs were underestimated, privatization opened the door for opportunistic providers who took advantage of every loophole (and there were many). As a result treatment suffered and costs skyrocketed. According to the *News & Observer*, in January 2005, the state told the federal government those two services, community support for children and community support for adults, would cost less than $5 million a month. By February 2007, when the Health and Human Services accountability team started an audit, the monthly bill was $93.5 million. The full series can be found at: http://www.newsobserver.com/2789/story/962049.html and includes these articles: **Part 1:** Reform wastes millions, fails mentally ill; **Part 2:** Companies cash in on new service; **Part 3:** Serious mental therapy fades; **Part 4:** Hospitals, nearly forgotten, teem with abuse; **Part 5:** Patients die from poor care.

Oregon
The Oregonian, November 4 – 10, 2007
After Fairview: How Oregon fails disabled adults

In the seven years since Fairview Training Center closed, more than 2,000 developmentally disabled adults have been robbed, beaten, raped, neglected or cursed, most often by their state-paid caregivers. Clients have choked on food, suffered violent injuries or become ill with treatable health problems that caregivers ignored or missed. In half the deaths investigated by the state, The Oregonian found that caregivers didn't recognize clients' serious health problems or act quickly enough to call 9-1-1. Their stories, archived in a state database and detailed in hundreds of confidential files obtained by The Oregonian, show that one of every five clients in state-licensed foster or group homes have been victims of at least one serious instance of abuse or neglect during the past seven years. The officials who oversee Oregon's 8,000 caregivers and 1,200 adult group and foster homes say they are working to protect clients. But the state has failed to close troubled homes, even after clients were raped or died. Officials also have been slow to adopt reforms in areas they acknowledge would make the system safer. See http://blog.oregonlive.com/oregonianextra/2007/11/grouphomes.html for full series.

California
CBS 5 Investigates, November 8, 2007
Bay Area Homes For Disabled

A CBS 5 Investigation raises questions about the quality of care in some for-profit group homes for the developmentally disabled. Our investigation begins with an incident in 2004 that happened at one Bay Area group home. Inside that home, Theresa Rodriguez, a woman with mental and physical disabilities had been badly burned. The home was run by RCCA Services. As a result of the scalding, the house was cited and fined by the state. And CBS 5 Investigates found that home was just one of three RCCA facilities in San Mateo County cited by the state for failing to meet federal standards. Two of those were cited for insufficient staffing, among other problems, and one was forced to shut down. CBS 5 Investigates also discovered the state recently found deficiencies at two other RCCA homes in San Jose. In January 2007, inspectors cited one of them, a home called Purple Hills, for failing to provide "continuous active treatment" for fully half of its clients.

Washington, D.C.
The Washington Post, September 15, 2007
Promises, Promises: The District has three months to show it can help its developmentally disabled residents.

The Washington, 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 noncompliance 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 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.

California
The Orange County Register, February 7, 2007
Taped Attacks Spur Outcry

A caregiver worked at a dependent-care facility for at least five months before a cellular phone surfaced that contained videos police said show him beating and taunting developmentally disabled men who cannot speak. "This isn't an isolated incident," Anaheim police Detective Cherie Hill said. "I think there's a lot more going on than we already know." State-licensed care facilities are required to run background checks on potential employees, but many aren't licensed and aren't required to do such checks, Hill said. "What else happened that wasn't taped?" Anaheim police Sgt. Rick Martinez asked. "Nobody would've ever known had it not been for that video."

Kentucky
The Lexington Herald-Leader, January 7, 2007
Deaths largely not investigated - Critics see gaping hole in care of state's mentally disabled

The woman, whose name was not released, is one of thousands of mentally disabled people who received care in group homes paid for by Medicaid. And she is one of 146 people who died over the past five years in the Supports for Community Living Home and Communtiy-Based waiver program, a network of 137 agencies that provides community-based services such as housing and counseling to 2,874 mentally disabled Kentuckians. Since 2001, the state has initiated on-site investigations in only 18 of the 146 deaths in the community living program, a Herald-Leader investigation found. Long-term mortality rates for mentally disabled people in community facilities are unknown. The department only started tracking deaths of the mentally disabled in the community in 2001. Thirty-eight of the 146 deaths since then were unexpected or sudden, according to the reports providers sent to the department. If any of those 146 people had died in a state institution in Kentucky their deaths would have been investigated by the Office of Inspector General with the Cabinet for Health and Family Services, and Kentucky Protection and Advocacy would have been notified. A mortality review board, made up of doctors and other specialists, also reviews all deaths in institutions. But the same review process doesn't apply when deaths occur in Kentucky's privately run, community-based care facilities. In those cases, only deaths deemed suspicious trigger an on-site investigation. The lack of in-depth investigation of deaths in the community is a gaping hole in Kentucky's protection of the mentally disabled, said Marsha Hockensmith of Kentucky Protection and Advocacy.

California
The Sacramento Bee, January 1, 2007
Conflict is boiling over care: The death of a severely retarded man is the latest flashpoint in a battle between families and the state over its developmental centers

Donald Santiago's mother and sister didn't want the state to move him out of the Agnews Developmental Center in San Jose, the state hospital where he had lived for nearly four decades. But state officials got a court order to move him into Justin's Home in Union City in 2005 over his family's objections. Santiago, 63, died of pneumonia in a Fremont hospital three weeks ago. The death of Donald Santiago -- being investigated by the California Department of Health Services -- is one more flashpoint in a wrenching battle between some parents of Agnews residents and the state, which has been under legal pressure to close its institutions and integrate residents with disabilities into their communities. Following changes in state law, the number of people living in developmental centers in California has dropped from a high of more than 13,000 in the 1960s to about 2,900 today. Three developmental centers have been shut down. Agnews, one of five remaining state centers for people with developmental disabilities, is slated to close in 2008. Only 261 residents remain. Some family members say they fear the state is hastily moving people into existing community homes that are ill-prepared to care for the severely disabled and don't have medical staff on-site, as Agnews does. Donald Santiago had the mental capacity of a 2-year-old and a vocabulary of only a few words, according to his sister, Angie Abrue of Placerville. But the state argued that Santiago had expressed a desire to leave Agnews in a 2005 court hearing before a Santa Clara Superior Court judge. Brian Boxall, president of the Association for the Mentally Retarded at Agnews, a group representing families, said the court system never should have ordered the move in the first place. "My sense of anger is most focused on the judge, the (district attorney) and the public defender who all orchestrated his placement knowing that his group home operator had these kinds of citations," Boxall said. "In that respect, Donald really was a victim of the system." Eileen Goldblatt, whose organization has assisted others in getting court orders but was not involved in Santiago's case, sees it differently. "It was our understanding that he got to court because he really wanted to move," she said. "It's tragic that he then died. It's also nice that he got to

Missouri
St. Louis Dispatch, December 20, 2006
Gov. Blunt orders Department of Mental Health to tell parents of sex offenders

The Post-Dispatch reported Monday that the state was placing people convicted or accused of sex offenses into privately run group homes and state-run facilities with other mentally retarded residents and was not notifying parents of the other residents. Gov. Matt Blunt said Tuesday that he was concerned about the report and that he had ordered the department to notify parents or guardians of others who share the group home with convicted offenders. He also ordered the department to ensure that all convicted offenders are registered with local police, as required by law. But the department will continue to keep secret the placement of people accused of sex offenses but not prosecuted because of their disability, saying state and federal law prohibit them from saying anything. Ron Nicholson, whose son was in a group home with a man accused of molesting a girl, said the new policy continues to put residents at risk. The man in the group home with his son had been determined to be incompetent to stand trial, so parents would not be notified of his presence under the policy. "I think it's atrocious. I think it's indefensible and unconscionable," he said. "They're knowingly and secretly putting known risks into group homes with non-risk individuals." The debate centers on about 50 people, and 31 of those are convicted sex offenders, department spokesman Bob Bax said. In three cases, the department discovered this week that it hadn't told police of the offender. In the rest of the cases, the department had notified police, although police didn't always list the offender on registries, Bax said. He said he thought that was because not all sex offenders are required to register. The debate comes as the Department of Mental Health already is undergoing major changes in how it reports and investigates abuse and neglect of residents, after a June series in the Post-Dispatch that found widespread mistreatment of residents and inadequate investigations of allegations.

Florida
The News-Press, September 20, 2006
Group Home Closed for Violations

Rodents and roaches. Chemicals left in unlocked cabinets. Electrical cords with wires exposed. A syringe in a kitchen drawer. Florida state inspections turned up those problems and others over nine months at 10 Professional Group Home, Inc. residences. The deaths of four residents and health and safety violations prompted the Florida Agency on Persons with Disabilities to shut down the Miami-based chain. The agency is required by law to monitor group homes once a year, but it does so at least once a month, officials report. Group homes are licensed by the agency and receive money through reimbursements from a Medicaid program for people with disabilities. There are 1,263 providers statewide. The homes are part of the state's emphasis on deinstitutionalization, taking people out of large institutions such as Gulf Coast Center. In one case, a Professional Group Home resident died just six weeks after he was moved from Gulf Coast center, where he had lived since 1994."

North Carolina
The News & Observer – August 13, 2006
53 Deaths in Five Years Tied to Adult-Care Violations

More than 50 people living in adult-care homes in North Carolina died recently after preventable mistakes. State records say that inattentive care, medication errors and poor maintenance of the homes contributed to the deaths over a five-year period. Residents of these assisted-living facilities, rest homes and family-care homes have choked to death, frozen, been scalded and wandered into traffic, according to reports on file with the state Division of Facility Services. One suffered a fatal stabbing by a fellow resident. Another received the blood thinner Coumadin for five days instead of Claritin, an allergy medicine. In each case, the deaths arose out of "something the facility did or failed to do," said Jeff Horton, the division's chief operating officer. For about

27,000 North Carolinians living in adult-care homes, the death rate after these preventable incidents is more than six times that of state residents over age 65 who die from health-care complications such as surgery gone wrong. These cases, in which people died after the staff or home committed serious violations, are just the ones reported to the state. Advocates for residents say more occur without notice. Outside of family and government, the deaths rarely get attention. A change in state law last year resulted in reduced public access to investigations and information about penalties in the cases. Since 2000, the state has dealt with 67 cases of preventable deaths in adult-care centers. The N&O analyzed 53 cases for which complete data were available and the most serious level of violation occurred, according to state records.

Washington, D.C.
Washington Post – August 5, 2006
D.C. Cleansed Group Home Death Reports; Court, Council Didn't See Unfavorable Information

The District government has altered reports concerning deaths of mentally retarded residents of the city's group homes, deleting damaging information before the documents were turned over to court officials and others who review the cases. The deletions, discovered by a federal court monitor, included information that described serious case-management failings; delays in obtaining consent for medical procedures; concerns about health care; concerns about autopsy findings and procedures; and problems getting information needed to complete the death investigations. One report was changed to remove several sentences critical of a case manager's oversight, including a complaint that he had visited the resident only once in eight years. The case manager still works for the Mental Retardation and Developmental Disabilities Administration, according to the court monitor, Elizabeth Jones. Jones frequently has faulted the city for the care and oversight of roughly 2,000 mentally retarded wards, most of whom live in group homes. In November, she said a pattern of neglect led to four deaths since late 2004, and she warned that other lives were in danger. In her latest report, Jones says the city also deleted some recommendations from the investigative contractor, the Columbus Organization that urged the mental retardation agency to change policies or practices to avoid future harm to group home residents, many of whom also have physical disabilities.

California
Inside Bay Area, July 3 – 5, 2006
Broken Homes

Some 26,000 of California's 200,000 developmentally disabled residents — people who are mentally retarded, have Down syndrome, are autistic or have other disabilities — get some type of community-based care, state data show, and many of them are in licensed care homes like The Circle-Los Altos, which are in residential neighborhoods all over the state. Many have been placed in care homes over the past dozen years, as the state emptied its institutions. Two state institutions for developmentally disabled people closed in the late 1990s and a third, Agnews Developmental Center in San Jose, is slated for closure in the near future. Many people are getting good services and leading happy lives in the community, those who work with them say. But others are being poorly cared for, according to the investigation of 300 care homes in Alameda, Contra Costa and San Mateo counties, which included more than 100 interviews and analysis of thousands of pages of public licensing reports and other documents spanning back to 1999. The investigation shows a care system whose low standards, poor funding and limited oversight spell trouble for the more severely disabled people it is now expected to serve — people the system was never set up for in the first place. And it shows that the state agency ultimately responsible for the welfare of the developmentally disabled — some of the state's most vulnerable people - has little direct involvement in their care. See, http://www.insidebayarea.com/brokenhomes

Missouri
Broken promises, broken lives, June 7 – 13, 2006
The St. Louis Post-Dispatch

A Post-Dispatch investigation has found abuse and neglect of mentally retarded and mentally ill residents in state centers and in private facilities the state supervises. Since 2000, there have been more than 2,000 confirmed cases of abuse and neglect with 665 injuries and 21 deaths.
http://www.stltoday.com/stltoday/news/special/abuse.nsf/Front?OpenView&Count=2000

Washington, D.C.
The Washington Post, June 24, 2006
Group Home Failures Persist - Care Still Lacking, D.C. Report Says

The District government continues to provide dangerous, substandard care to disabled residents at some of its group homes and has recently hampered oversight efforts by failing to provide full and timely information on critical operations, a federal court monitor has found. In her latest quarterly report, court monitor Elizabeth Jones describes numerous and chronic problems with the city's Mental Retardation and Developmental Disabilities Administration. She also questions whether she is getting complete reports on death investigations, saying that at least one document she received from the District was edited to remove information critical of the city. A review of five deaths between late 2004 and late 2005 showed that recommendations issued after death investigations weren't always shared with direct care providers, putting group home residents at risk, she said. "The continuing failure to remedy critical systemic issues of substandard care, treatment and oversight means that other clients will experience needless pain, delayed or non-existent attention to high risk situations involving health and safety, and unnecessary threats to their very existence," she wrote. "The urgency to remedy these systemic failures could not be greater."

Connecticut
Hartford Courant, June 12, 2006
Agency criticizes agency responsible for mentally retarded

A state agency, reviewing deaths of mentally retarded clients, is critical of the quality of health services provided by the state Department of Mental Retardation. The Fatality Review Board for Persons with Disabilities has concluded that the DMR contributed to the deaths of dozens of mentally retarded people in its care because it failed to provide them with adequate health care services. The report, released Friday, pointed to what it said were key weaknesses in the DMR's health care services including inadequate coordination of services for people living in the community, the discharge of hospital patients into shoddy nursing homes and insufficient nursing care. The report summarizes the board's review of DMR client deaths from July 2003 through June 2005. The board reviewed the deaths of 361 clients, ranging from people who live in state institutions to those living independently or with family, and conducted 35 in-depth investigations. The board found abuse or neglect in many of the cases. The mental retardation agency is reviewing the findings of the board and plans to use them to enhance the agency's existing efforts to improve its health and safety programs, according to a statement the DMR released Friday. It said it has already enacted some of the board's previous recommendations.

Virginia
Times-Dispatch, December 18, 2005
New stakes for study of group homes

A legislative study of group homes is expected to produce proposals for new laws to toughen the regulation of group homes in Virginia and require a closer look of how public money is spent on the care of troubled youths.

For state and local policymakers, there is evidence that Virginia isn't doing a good enough job in making group homes accountable for the care they provide at public expense under the Comprehensive Services Act, or CSA.

"The state has a laissez-faire approach to regulation and monitoring," he said, "resulting in a system that is extremely costly and not necessarily providing the quality of care that the kids deserve."

A legislative subcommittee plans to introduce legislation that would:

- Make the state put the new law into effect immediately.
- Tighten the standards for licensing and regulating group homes.
- Order a study by the Joint Legislative and Audit Review Commission of the rates charged under the Comprehensive Services Act, which pays for treatment of children primarily through a combination of state and local funds. The federal Medicaid program also contributes money for care under the system.

The state licenses and regulates group homes, as well as other kinds of treatment facilities, through four different agencies that in some way handle children with problems. The system includes children in foster-care, special-education and mental-health programs, and the juvenile-justice system.
[Internet: http://www.timesdispatch.com]

Washington, D.C.
The Washington Post, November 29, 2005
4 Deaths in D.C. Group Homes Raise Concerns About Neglect

The District government is failing to provide adequate care for mentally and physically disabled residents in its group homes, according to a court monitor who found that a pattern of neglect led to four deaths in the past year. One woman and three men "are dead because they did not receive timely and competent health care," court monitor Elizabeth Jones said in a newly released report. Jones expressed "grievous concerns" about the health and safety of hundreds of disabled people who live in the group homes, especially those with special health risks. The deaths, she warned, "reflect the lack of meaningful safeguards in the system." The four deaths might have been prevented if the city's Mental Retardation and Developmental Disabilities Administration had followed up on earlier recommendations for improving care in the homes -- and if the agency's case managers had been more vigilant in addressing critical problems, wrote Jones, whose staff reviewed medical records and death investigations. Sandy Bernstein, legal director for University Legal Services, which represents the plaintiffs in the suit against the District, criticized what she called "short-term approaches" to dealing with such serious failings by the city. The suit covers about 700 plaintiffs, all former residents of Forest Haven, a now-defunct institution for the mentally retarded. Another 1,300 plaintiffs are special-needs clients of the agency.

Washington State
Seattle Post Intelligencer, Nov. 16 – 18, 2005
Public Protection, Private Abuse (Mentally disabled preyed upon in state system)

11 articles in a three part series look at for-profit companies, contracted by the state, to closely supervise dangerous developmentally disabled people in the community. While the costly program does protect the public in many cases – most of the clients are sex offenders – it has left other vulnerable adults with developmental disabilities at risk of abuse and neglect.

The investigation of the Community Protection Program was based on multiple public disclosure requests to the Department of Social and Health Services which led to the release of more than 12,000

pages of documents. That included incident reports, recertification reviews of residential providers, financial reports and policy documents. http://seattlepi.nwsource.com/specials/protect/

South Carolina
The State, October 28, 2005
State needs investigators to handle abuse and neglect cases, group says

Reports of abuse and neglect of disabled South Carolinians are too often mishandled and those responsible are rarely held accountable, according to a watchdog group. Protection and Advocacy for People with Disabilities Inc. released a report on a two-year study Thursday, highlighting 50 cases that included physical and sexual abuse and deaths in state-funded community-based residential facilities. The authors, who focused the study on the state Department of Disabilities and Special Needs, say the report portrays a broken system that provides little protection for those who cannot protect themselves. The report found flaws in the way many of the cases were handled, stemming largely from the practice of allowing facility administrators to conduct their own investigations into abuse claims rather than alerting law enforcement immediately. The state should create an independent agency, preferably within the State Law Enforcement Division, to investigate all abuse claims immediately, the report says. The agency would include specially trained investigators who know how to work with mentally disabled adults. The issue of abuse at state-funded care facilities came to the fore in recent years when a series of audits of the Babcock Center uncovered cases of abuse, neglect and exploitation of its residents. [Internet: http://www.thestate.com]

National
The Wall Street Journal, September 20, 2005
Difficult Choices: Needing Assistance, Parents of Disabled Resort to Extremes

Nationwide, an estimated 80,000 developmentally disabled people are waiting for in-home help or an opening in a group home. Some have been on waiting lists for more than a decade. In Texas, there are 46,000 people waiting for such help -- or about four times the number of people actually receiving assistance. Requests are increasing as the nation's 4.6 million developmentally disabled, like the rest of the population, are living longer. Meanwhile, their parents are aging too, making it harder to keep up with caretaking.

Long waits for help have prompted lawsuits in two dozen states, charging violations of a 1999 Supreme Court decision requiring states to make diligent efforts to serve disabled individuals in their community. Florida settled one suit in 2001, promising services to 17,000 people on waiting lists. By increasing spending, it did. Since then, the waiting list has ballooned again, to more than 15,000.

Indeed, even though public spending to provide community services to people with developmental disabilities grew by 17% between 2000 and 2002 – to about $27 billion -- demand for those services continues to outpace availability. Federal funds, primarily Medicaid, provide 50% of that $27 billion, with states kicking in 46% and local funds the remaining 4%.

"Unless you're in a crisis, you don't get services. I'm sure that's the case in most states," says Tony Paulauski, executive director of ARC of Illinois, part of a national, nonprofit organization for the developmentally disabled.

National
The Wall Street Journal, September 13, 2005
Safe Place: Disabled People Find Group Homes Can Be Broken too – Patients Gain Independence, But Oversight is Spotty; Challenges of Monitoring

Over the past three decades, there has been a concerted effort to move people with developmental disabilities out of large institutions, which had been long criticized for being overcrowded and isolated. A widely lauded effort to move people into smaller group homes has succeeded in bringing the developmentally disabled into communities where they can learn new skills, get jobs or attend special schools. But this progress has come at a price. It has strained the systems that support people living in the smaller settings and created big gaps in oversight.

Twenty-five years ago, people with developmental disabilities lived in about 16,000 publicly funded homes. Today, they are scattered in about 140,000.

"The systems of quality monitoring have really been taxed beyond what they can manage," says Charlie Lakin, who heads a University of Minnesota program that tracks services to the developmentally disabled. "By and large, a lot of it is pretty loosely organized and pretty loosely monitored."

Only a half-dozen states require that residential programs serving the developmentally disabled be accredited by an independent third-party organization. Developmental disabilities, which affect about 4.6 million people in the U.S., include a range of mental and physical impairments, such as cerebral palsy, autism and mental retardation. Babcock (South Carolina community provider) offers a stark look at the flawed monitoring of group homes, which sometimes leaves family members and other advocates feeling they need to police the care themselves.

The U.S. Department of Health and Human Services -- which pays about half of the $27 billion spent annually on community services for the developmentally disabled -- is ultimately responsible for their protection. But the federal agency assigns the creation and enforcing of rules over such homes to each state. As a result, laws and monitoring vary by state. States aren't required to report all incidents of abuse or neglect to the federal agency. The federal government typically only gets involved if families, advocates or employees of homes provide credible concern about the thoroughness of a state investigation. HHS, which oversees the Centers for Medicare and Medicaid Services, is drafting new procedures following a 2003 report from the General Accounting Office, saying states should be required to report more information about how they protect people with developmental disabilities.

Thousands of nonprofit group homes offer well-supervised programs for the developmentally disabled. But problems exist to some degree in nearly every community, says Curtis Decker, executive director of the National Disability Rights Network, a nonprofit group. Investigators may overlook flaws, he says, because of a lack of other housing options. "They don't know what to do with these folks if they closed a place down." The number of abuse and neglect cases among the developmentally disabled isn't collected nationwide. Many states don't keep central databases on employees involved in such cases, allowing workers to move from one agency to another. "You put people in tough jobs, who are underpaid, not well-trained or supervised, and the potential for abuse is big," says Mr. Decker. "It's endemic to the country."

Missouri
Missouri State Auditor, September 2005
Report No. 2005-62: State mental health clients not fully protected from abuse and neglect due to problems with incident investigations and abusive workers still employed

This audit reviewed how well the Department of Mental Health tracks, investigates and handles incidents and investigations of individuals committing abuse or neglect against its 140,000 clients. All such allegations, including client deaths are tracked in the department's Incident and Investigation Tracking System, which reported 5,689 incidents from July 2003 through August 2004. This audit also followed up on recommendations from a 2001 audit and found systemic problems with abuse investigations. The audit found continuing problems in several areas, including continued employment of known felons and abusers, leading to more abuse, and

overall lack of independence and consistency in abuse investigations. [Internet: http://www.auditor.state.mo.us/press/2005-62.pdf]

Maryland
The Baltimore Sun, April 10-17, 2005
A failure to protect – Maryland's troubled group homes.

In an investigation of state oversight of group homes going back a decade, The Sun found that:

- Mistreatment of children has gone unpunished.
- People with criminal convictions can -- and do -- work at group homes.
- Taxpayers' money is often wasted on poor care, denying youths a range of services.
- Maryland subsidizes high salaries and perks.

The Sun examined the regulation of care, spending and staffing at 25 companies that ran 120 homes for children. Reporters studied 15,000 pages of inspection reports, case files and other records obtained under the state's Public Information Act and conducted more than 150 interviews.

[Internet: http://www.baltimoresun.com/news/local/bal-grouphomes,1,270369.special?ctrack=1&cset=true].

Florida
The Miami Herald, March 26, 2005
Deaths at group homes being probed

In light of cost-cutting changes in nursing care, an investigation is under way into the deaths of four disabled Floridians at group homes. A federally-funded watchdog group is investigating the recent deaths of four disabled Floridians amid an aggressive state campaign to cut millions of dollars from programs that provide medical care for disabled people in community settings. In 2001, the state hired a private company, Maximus Inc., to look for ways to save $24 million annually. The company's actions have been upheld in 97 percent of the appeals to state officials. Advocates for the disabled insist the quality of medical care for disabled people in group homes has suffered since September when Maximus and the state began requiring group homes to pay for nursing care from the state's Medicaid plan. That plan covers rotating nurses, not the more stable nursing care provided under a previous plan for disabled people. [Internet: http://www.herald.com]

National
People with Mental Retardation & Sexual Abuse
The Arc of the United States
(author: Leigh Ann Reynolds, M.S.S.W., M.P.A., Health Promotion & Disability Prevention Specialist)

More than 90 percent of people with developmental disabilities will experience sexual abuse at some point in their lives. Forty-nine percent will experience 10 or more abusive incidents (Valenti-Hein & Schwartz, 1995). Other studies suggest that 39 to 68 percent of girls and 16 to 30 percent of boys will be sexually abused before their eighteenth birthday. The likelihood of rape is staggering: 15,000 to 19,000 of people with developmental disabilities are raped each year in the United States (Sobsey, 1994). [Internet: http://www.thearc.org/faqs/Sexabuse.html]

North Carolina
The Charlotte Observer, January 16, 2005
Millions Wasted – The Cost of Kids' Lives

Since 2001, the state has wasted tens of millions of dollars paying group homes for workers who were never hired, making the industry so lucrative that hundreds of new homes opened – so many that the state couldn't regulate them. The error helped create a system that's failing some of the state's most vulnerable youngsters and cheating taxpayers who pumped more than $165 million into homes last year. In the past three years, as group homes multiplied and regular inspections ceased, many group home owners exploited the system's weaknesses. Many ignored even the state's minimal standards, putting children at risk. [Internet: http://charlotte.com].

California
California Department of Developmental Services (DDS), October 27, 2004
California Releases Mortality Studies

During the late 1990s, a series of epidemiological studies of death rates in California mental retardation institutions compared community residential settings was issued by the University of California Riverside. These reports found risk of mortality to be 83% higher in community settings than in institutions (see, http://www.lifeexpectancy.com, link Articles, Comparative Mortality). These studies prompted the California Department of Developmental Services to commission two follow-up studies. Comparing quality of care provided by developmental centers, community care facilities, intermediate care facilities and other settings, the report indicates, "there were few statistically significant differences in the quality of care, "though it was noted that the developmental centers provided a 'higher quality of care.'" One problem in determining the adequacy of health care for this study was the lack of documentation. Except for developmental centers, the lack of documentation was an issue for all other types of facilities. Another issue pointed out by the authors of the report is the need for health education appropriately geared for the developmental level of the consumer. An earlier report (1994) noted that "residents at developmental centers were significantly less likely to die from preventable causes than those residing [in] skilled nursing facilities, intermediate care facilities, or community care facilities." The preventable deaths were primarily due to "inadequacies in the quality of care" followed by "inadequacies in the medical management of common health concerns."

The three reports can be found on the Department of Developmental Services website:
http://www.dds.cahwnet.gov/mortality/mortality_home.cfm
http://www.dds.cahwnet.gov/mortality/PDF/CSUS_Final94_Report.pdf
http://www.dds.cahwnet.gov/mortality/PDF/CSUS_Final99_Report.pdf

Maryland
The Baltimore Sun, August 1, 2004
Safeguards meant to protect the disabled in Maryland group homes failed this time

Toby Adele Heller died of colon cancer 11 months after caretakers failed to follow a physician's advice to see a gastroenterologist. Toby's case exposes holes in the state system of care for 5,000 people with developmental disabilities living in licensed group home facilities. Employee turnover is high – 42 percent a year among aides – and wages are low. Even with the recent state-imposed increases, caregivers on average make less than $10 an hour. Quality of care varies with their skills and compassion. And regulators rely heavily on the facilities and families of residents to report problems. But, with nearly 7,000 people on a waiting list for residential services, relatives are often afraid to complain, fearing that their loved ones would have nowhere else to go. Still, Toby's family, like other families, had every reason to expect that she was getting good care: The state was paying top dollar for her to receive round-the-clock staffing at a cost of $127,672 a year. Her provider, Autumn Homes, received $2.6 million from the state to provide services for 32 clients in 2003.
[Internet Access: http://www.baltimoresun.com]

Virginia
The Washington Post, May 23 – 27, 2004
Assisted Living in Virginia

In a series of articles this week, The Washington Post reported that residents at the facilities have suffered thousands of incidents of harm, including death, abuse, neglect and serious injuries. The state is home to 627 facilities licensed to care for more than 34,000 residents who need supervision and care but who are not sick enough to qualify for a nursing home. The problems stem from several causes, including poor staff training, insufficient resources and relatively weak enforcement by state regulators, according to records and interviews. [Internet Access: http://www.washingtonpost.com]

Michigan
The Detroit News, May 5, 2004
Group home abuses escalate

The March 29 beating joins a growing number of complaints about abuse at Michigan group homes, where many of the state's most vulnerable citizens are cared for by employees with low wages and limited training. Last year, the state of Michigan fielded 1,898 complaints about adult group home conditions. That represents a sharp rise compared to 2002, when there were 1,300 total complaints statewide. An estimated 35,000 people live in more than 4,200 state-licensed adult foster care facilities in Michigan. In general, the staff members are paid fast-food wages and given about two weeks of training before they take over the care of the mentally ill and developmentally disabled adults in the homes. [Internet Access: http://www.detnews.com/2004/metro/0405/05/a01-143514.htm]

Massachusetts
The Patriot Ledger, March 20 – 23, 2004
Special Report: Retarded at risk; System failures

When it comes to medical care, some of the state's most vulnerable residents, the 8,700 adults who live in group homes for persons with mental retardation, are treated as second-class citizens. Since 2002, three group home residents died because of medical neglect and nine other deaths are under investigation. Since 1999, more than 260 cases of physical abuse and medical error involving the disabled have been substantiated each year. Often, when something goes wrong, on one is held accountable.
[Internet Access: http://www.southofboston.net/specialreports/retardedatrisk]

Virginia
The Virginia Pilot, February 29, 2004
Special Report: Virginia's treatment of the mentally disabled

Was it truly their time to die, or could their deaths have been prevented? The answers are difficult to find, mostly because the state, which used to be the primary caregiver for the mentally disabled, has surrendered much of that role to a patchwork system of community-based programs, such as group homes. The homes, 106 of them in South Hampton Roads, operate with low-paid, minimally trained workers. They churn along with a steady stream of money from the state and federal government, but with little oversight from either. The state employees 12 inspectors to monitor 2,468 mental health, mental retardation and substance abuse service locations, including group homes. That's an average caseload of 206 locations per inspector. A single inspector has responsibility for all of South Hampton Roads, except Portsmouth. Accidents and injuries are supposed to be self-reported by the provider, but may go unreported. Deaths do not have to be reported to the medical

examiner. State records that do exist show problems. Of 34 group home providers in South Hampton Roads, 18 have been cited for state licensing violations and 11 for client abuse or neglect in the past three years. The state has legal authority to fine violators but never has done so. Only one provider's license has been revoked in the past three years. [Internet Access: http://www.hamptonroads.com/pilotonline/]

Indiana
The Times Newspapers of Northwest Indiana/S. Chicago, January 25, 2004
Caring for our invisible citizens; Developmentally disabled caregivers often overworked, undertrained, unqualified

A severe shortage of direct care providers across the country has stemmed from a mass exodus of state institutional care. The result is an annual turnover rate ranging from 50 to 75 percent due in part to low wages. Indiana had no state standards for direct care providers until late 2002. These standards, however, still allow the hiring of individuals regardless if they have employment experience or training of any kind. In addition, no required registry exists for these employees if they are fired from one agency for alleged neglect or abuse and then hired at another agency. Critics said the old threat of state-run institutionalized care has been replaced by a new danger - the big business of private care. That machine is fed by money from the Medicaid waiver program, a financing arrangement that relieves clients from traditionally strict care regulations. In 2003, Indiana's Family and Social Services Administration received 467 formal complaints against some of the approximately 850 approved private providers. Some complaints were minor, some more significant, resulting in corrective actions.

New Mexico
The Albuquerque Journal, November 18, 2003
State Probes Abuse of Disabled

Gov. Bill Richardson has ordered an independent inquiry to track down former residents of the now-closed Los Lunas Hospital and Training School. Richardson's order follows publication of news stories about three developmentally disabled women who were discharged from the Los Lunas facility more than 20 years ago and placed in the unlicensed home of a staff housekeeper and her husband. The goal of the investigation announced Monday is to find whether any more of the former residents may have "slipped through the cracks," receiving no state services and no monitoring. [Internet Access: http://www.abqjournal.com]

New Mexico
The Albuquerque Journal, November 3, 2003
Judge Won't Halt Disability Suit: State's Request for Stay Rejected

The Jackson class action lawsuit, filed in 1987, resulted in the closure of Los Lunas and Fort Stanton State Developmental Centers and the court-ordered transfer of residents into group homes and other community settings. In 1997, the parties reached an agreement intended to be a blueprint for ending the lawsuit once certain benchmarks were reached. Oversight has since ended in about two-thirds of the areas. The state's motion to dismiss the case, arguing that all requirements have been met, failed in light of evidence that there remained pronounced shortcomings in providing safety for New Mexicans with severe disabilities. Attorney for the plaintiffs, Peter Cubra, told the judge that there had been more than one death of class members per month over the past 20 months. The state lacks an effective system for dealing with neglect and abuse when it occurs and for preventing its recurrence, plaintiffs argued. Arc attorney Maureen Saunders cited instances where guardians for clients had learned of problems at group homes operated by contract providers and had informed both providers and the state about them. She said she received no response or one that was delayed for months. [Internet Access: http://www.abqjournal.com]

Illinois
The Chicago Tribune, September 1, 2003
Report blasts group homes – Dirty, unsafe conditions cited

Developmentally disabled residents of six Chicago-area group homes endured filthy and unsafe living conditions, frequently going without toilet paper, while the homes' owners spent thousands of dollars of leased cars and other perks, a disability-rights watchdog group said in a new report. Surprise inspections at the homes, operated by These are God's People Too, found dark, "foul-smelling" homes, walls smeared with feces, bathrooms without toilet paper and "unkempt yards strewn with garbage," said the report by a non-profit group that the state has designated to "protect and advocate" for the disabled. The investigation, conducted from March 2002 to June 2003, also found safety hazards, such as blocked exits and easily accessible cleaning products, as well as staff members unfamiliar with proper techniques for restraining unruly residents, the report said. [Internet Access: http://www.chicagotribune.com/]

National
Policy Research Brief (University of Minnesota), September 2003
Medicaid Home and Community-Based Services: The first 20 years

HCBS and other community services for persons with mental retardation and developmental disabilities have grown at an extremely rapid rate during the past decade. This growth and the nature and flexibility of HCBS have brought enormous challenges in monitoring of service quality and protecting persons receiving them. States have not been able to expand quality assurance (QA) systems commensurate with this growth. But even if they had, they would have had to adjust to new expectations. What was considered "quality" in community services in 1982 or even in 1992 no longer satisfies contemporary values. Today, definitions of quality in human services require attention to dimensions of quality of life in addition to protection of health and safety. A few states have established systems for quality review that attend to the new concepts of quality (see Bradley & Kimmich, 2003; www.qualitymall.org) and over the past decade there have been persistent concerns about whether they attend sufficiently even to the basics of health and safety. A March 19, 1993, House hearing called by Rep. (now Senator) Wyden examined the quality of community services and concluded, "State public officials charged with their oversight had little or no knowledge of the conditions within their homes…or at best found out only after terrible events had occurred." The Wyden hearing was followed by newspaper stories of the inadequate, life-threatening, sometimes life-ending quality in community services published in several major newspapers in the late 1990s and early 2000s (e.g., Washington Post, San Francisco Chronicle, Minnesota Star Tribune, Hartford Courant). They stimulated emotional reactions, defensive responses, and promises to do better. But, in June 2003 the General Accounting Office (GAO) issued a new report critical of QA in Medicaid HCBS. Although focused primarily on HCBS for elderly people, it recommended that the federal government: "1) establish more detailed criteria regarding necessary components of HCBS QA systems; 2) require states to submit more specific information about QA approaches prior to approval; 3) ensure that states provide sufficient and timely information in their annual reports on efforts to monitor quality; 4) develop guidance on the scope and methodology for federal reviews of state programs; 5) ensure allocation of sufficient resources for conducting thorough and timely reviews of quality in HCBS and hold regional offices accountable for such reviews" (GAO, 2003, p. 5). Clearly, addressing challenges of creating effective quality assurance systems will require leaders that believe that the safety, well-being and quality of life of people with mental retardation and developmental disabilities deserves public investment in a time when other substantial needs are competing for that investment. [Internet Access: http://ici.umn.edu/products/prb/143/]

Colorado
The Denver Post, August 11, 2003
State Medicaid program a mess, participants say; Oversight at issue in waiver care

Medicaid clients and advocates report failures by state officials to adequately monitor the care patients received through the state home and community-based waiver program. State regulators have known about holes in quality oversight since a scathing report two years ago, but say that policing home care is tough with the little power state legislators have given them. Complaints range from theft and negligence by in-home caregivers to allegations that aides forced patients to sign false time sheets and that caseworkers kept people from qualifying for service. Some clients say they've waited for years for the state to address complaints about shoddy service or forgotten care – with no response. A report issued by the Colorado state auditor in June 2001 found that investigators of Medicaid waiver-related complaints sometimes waited months to follow-up, spent far less time investigating complaints than other states did, kept inadequate records of investigations, and were far less likely than investigators elsewhere to cite health providers with deficiencies even after multiple complaints.

National
U.S. General Accounting Office, July 2003
Long-Term Care: Federal Oversight of Growing Medicaid Home and Community-Based Waivers Should Be Strengthened (Report No. GAO-03-576)

Despite a growing number of home and community-based waiver beneficiaries (up to almost 700,000 as of 1999), State waiver applications and annual reports for waivers contain little or no information on state mechanisms for assuring quality in waivers, thus limiting the information available to the federal government. GAO's analysis of available federal and state oversight reports for waivers serving beneficiaries identified oversight weaknesses and quality of care problems. More than 70% of the waivers that GAO reviewed documented one or more quality of care problems. The most common problems included failure to provide necessary services, weaknesses in plans of care, and inadequate case management. The full extent of such problems is unknown because many state waivers lacked a recent CMS review, as required, or the annual state waiver report lacked the relevant information. GAO recommends strengthened federal oversight. [Internet Access: http://www.gao.gov/cgi-bin/getrpt?GAO-03-576]

Georgia
The Atlanta Journal-Constitution, February 24, 2003
Agency failed clients; Poor service may be linked to 6 deaths

Mismanagement by a state-funded community service board in northwest Georgia might have contributed to the deaths of six disabled people, according to a written state review. A scorching report on the performance of the Highland Rivers Community Service Board also found payments to employees who might not exist; long delays in serving mentally ill and mentally retarded patients; and high staff turnover. The state Department of Human Resources has given Highland Rivers until the end of February to come up with a plan for fixing 12 "critical" problems cited in the report. Highland Rivers has another month to address the other issues noted in the 30-page report.

Massachusetts
The Boston Globe, February 4, 2003
Audit alleges misuse of $1 million

Since 1997, the state Disabled Persons Protection Commission has investigated 19 complaints of client injury at Community Group, Inc., facilities and substantiated three cases involving neglect. Another six cases are

pending. Officials said they were concerned about the well-being of many of the 85 clients the firm was caring for at 21 group homes in Eastern Massachusetts. The for-profit company was hired by the state to provide housing and job training for people with mental retardation. In addition to the accusations relating to poor care, a state audit recently found that the company had secretly raised more than $1 million selling products made by its clients with disabilities and used the money for a Mercedes-Benz, country club membership, and other perks for company management. Community Group, Inc. of Wakefield also kept $673,000 in profits from group homes and support services – three times the amount allowed by its approximately $4 million contract with the state. The state Department of Mental Retardation fired the company last fall, accusing it of providing poor care, in addition to the alleged financial misdeeds.

Connecticut
The Hartford Courant, January 4, 2003
Study: DMR Clients Died Needlessly

A legislative committee has concluded that some mentally retarded residents of group homes in Connecticut needlessly died "tragic" deaths, which were then not investigated properly because poor oversight by state agencies. In a voluminous report on group home deaths, the Program Review and Investigations Committee also found that the state Department of Mental Retardation created a conflict of interest by investigating deaths itself, and said it should transfer that responsibility to another state agency. The legislature late last year asked the committee to review deaths in DMR group homes after a Courant investigation found evidence of neglect, staff error or other questionable circumstances in one out of every 10 deaths over the past decade. As part of the lengthy report, the committee reviewed the 36 cases identified by The Courant and 177 others chosen randomly to see if there were any patterns of neglect. The committee report concluded: "Tragic things happened that but for a different set of circumstances might not have." It also pointed out that systems were in place to address the risks to DMR clients, but for one reason or another were not carried out.
[Internet Access: http://www.ctnow.com].

Wisconsin
Milwaukee Journal Sentinel, December 13, 2002
Assisted living sites go without inspection; Audit finds citations rose 140% in 3 years

Nearly half of the 2,114 assisted living facilities that care for the elderly and people with disabilities went more than a year without a visit from a state regulator, an audit report revealed Friday. The lack of state scrutiny came at the same time that complaints and citations against such assisted living homes and apartments in the state were increasing, according to the report from the Legislative Audit Bureau. State legislators requested the review in October 2001, after a series detailed how residents in assisted living facilities had died or been injured because of inadequate care or supervision. The series also showed that the state's regulation had fallen behind the growing industry, which expanded from 1,824 facilities to 2.114 from 1998 to 2001. The capacity of the facilities grew even faster, jumping 35% over the three-year period. At the same time, the number of field inspectors assigned to scrutinize assisted living facilities by the state Bureau of Quality Assurance has decline from 23 from 26. **[Internet Access: http://www.legis.state.wi.us/lab/Reports/02-21full.pdf].**

Ohio
Cincinnati Enquirer, September 2002
Ohio's Secret Shame

In two previous installments of Ohio's Secret Shame, the *Enquirer* revealed that the state mental retardation system is so chaotic that it routinely fails to prevent deaths, correct problems or enforce minimum standards of care. The well-being of 63,000 mentally retarded people depends on the system, which taxpayers fund with $1.8 billion every year. Among the newspaper's findings thus far: 80 to 120 mentally retarded people die each year from choking, drowning, abuse, neglect or other avoidable causes. That's one of every seven deaths in the

system; Reports of neglect, abuse, and other serious incidents have quadrupled in the past four years. Yet there's little public accounting; and Caregivers who abuse and neglect mentally retarded people rarely are punished. [Internet Access: http://enquirer.com/mrdd].

Washington State
Seattle Post-Intelligencer, July 27, 2002
Audit blasts DSHS services for disabled

A $250 million-a-year state program serving about 11,700 developmentally disabled Washingtonians is so poorly run that it jeopardizes the health and welfare of its client and violates federal law, a federal audit has found. The report concluded that Washington provided services through the federally subsidized program to more than 5,000 ineligible people over 4 ½ years — and the feds want millions of dollars back. The report also found that the state unfairly denies services and inappropriately handles appeals of service denials. The state further provides shoddy financial accountability. The review was conducted by the Centers of Medicare and Medicaid Services and looked at the Department of Social and Health Services' operation of the waiver program which is intended to offer community-based alternatives to institutionalization for people with mental retardation, cerebral palsy, epilepsy, autism and similar conditions.
[Internet Access: http://seattlepi.nwsource.com/local/80326_audit27.shtml]
[CMS Report: http://www.wa.gov/dshs/mediareleases/pdf/CAPWaau.pdf]

Maryland
Baltimore Sun, July 21, 2002
Violence raises concerns over group homes

The killing of a caretaker this month at an Ownings Mills group home for the mentally ill — the latest in a series of violent incidents at assisted-living centers — has renewed concerns about the state's ability to regulate such facilities. In several incidents this year, a state review uncovered serious problems, including inadequate staff training and supervision. And although state officials acknowledge that as many as 1,000 unlicensed group homes may be in operation, there are no inspectors dedicated to finding them. In every case of violence, officials found problems. There were too few staff members supervising the group homes, not enough training for caretakers, and inadequate screening of residents and staff for histories of violent or criminal behavior. The number of hospital beds for the mentally ill has steadily declined as a result of recent cuts in stte funding for mental health and deinstitutionalization, a movement to transfer such patients from long-term institutions to community settings. [Internet Access: http://www.sunspot.net/news/local/bal-md.home21jul21.story]

New Jersey
The Bergen Record, June 23, 2002
N.J. finds dangers in group homes

State inspectors uncovered violations that jeopardize the health and safety of disabled people in more than half of the 86 group homes in Bergen and Passaic counties. Inspection reports reviewed by The Record found dozens of instances where residents were given improper medication or failed to receive prescribed treatments. The 136 reports, which covered a four-year period, also cited homes for employing untrained staff and failing to keep complete records. An increasing number of people with autism, cerebral palsy, and other disabilities are living in group homes. In 1992, about 1,590 people lived in 260 group homes statewide. Today, 742 homes, run by 106 private agencies, house nearly 3,400 people. The agencies receive state funds to operate the homes. [Internet Access: http://www.northjersey.com]

Kentucky
State Audit Report, May 2002

Kentucky can better serve mentally retarded/developmentally disabled persons, State Auditor Ed Hatchett announced today that a performance audit of Kentucky's community-based services for people with mental retardation and developmental disabilities has raised questions about the failure to report abuse, the quality of care provided, and the number of persons served. The audit examined 210 incidents of alleged abuse, neglect, or exploitation and found that Kentucky's Cabinet for Families and Children (CFC) had reported only 19 to law enforcement. In addition, one of these cases were reported to the Attorney General's Office in spite of a contractual agreement obligating the Cabinet to refer all cases "which exhibit substantial potential for criminal prosecution . . ." The audit also revealed that SCL providers as well as the Cabinet for Health Services have frequently failed to inform the Cabinet for Families and Children of incidents of neglect and abuse. [Internet Access: http://www.kyauditor.net/Public/Audit_Reports/Archive/2002MRDDPerformance-PR.htm]

Maryland
Washington Post, May 8, 2002
Md. concedes failings of group home system

Maryland health and child welfare officials acknowledged this week that they have not adequately monitored the patchwork of complaints that run more than 300 group homes for troubled youth, including a Wheaton home where a 14-year-old girl committed suicide. Last fall, mounting evidence that several group homes were leaving unstable children in the custody of untrained, poorly paid workers prompted Gov. Parris N. Glendening (D) to convene a task force to propose an overhaul. But months later, he rejected the key steps the pane had offered in an October report because the state could not afford the added $3.8 million in costs, one of his aides said. In meetings with the task force last year, advocates complained that no central agency is monitoring complaints about group homes. Homes that were cited by the Department of Health and Mental Hygiene may still have clean records with the Department of Human Resources or the Department of Juvenile Justice. [Internet Access: http://www.washingtonpost.com]

New York
The New York Times, May 29, 2002
Here, life is squalor and chaos

Federal prosecutors in Brooklyn and Manhattan said yesterday that their offices were investigating adult homes for the mentally ill in New York City to determine whether poor conditions in the homes resulted from criminal conduct by their operators and health care providers. F.B.I. agents have begun interviewing current and former workers at the homes, and prosecutors said they would focus on whether the operators or health care providers had defrauded federal aid programs, siphoning off money that should have been spent on care for the residents. Their action came after a three-part series in The New York Times that laid out neglect and misconduct in private, profit-making homes, which are regulated by the state.

Ohio
Dayton Daily News, February 3, 2002
There are deaths that are preventable

As it stands on the brink of its most sweeping overhaul since deinstitutionalization began three decades ago, Ohio’s $1.85 billion system to protect 63,000 people with mental retardation is riddled with gaps that have deadly consequences. Since 1997, at least 30 people with mental retardation in Ohio have died from neglect while in the care of others. These people died from chokings, drownings, bowel obstructions, accidents, malnutrition or other causes that experts say are preventable or can be successfully treated. The system is so

enshrouded in secrecy that fatal mistakes are often hidden from the public. But an 18-month Dayton Daily News examination, which included more than 200 interviews and a computer analysis of 400,000 Ohio death records from 1997 - 2000, found a pattern of neglect toward the state's most vulnerable citizens. [Internet Access: http://www.activedayton.com/ddn/local/0203mrdd.html].

Ohio
Cincinnati Enquirer, February 2002
Ohio's Secret Shame

At least 12 Ohioans with mental retardation, and probably more, have died in questionable circumstances in the past four years. Deaths from all causes jumped 78 percent, and reports of neglect and other serious incidents quadrupled. Yet there's little public accounting. Some county caseworkers are supposed to watch over 125 people at once, five times the state's recommended number. Taxpayer support is so uneven that one Ohio county spends $43,800 a year on each person with mental retardation, while another spends just $2,800. Articles in the investigative series include, "Twelve who died," "Unequal System," "Who is accountable," "Slow reform," "Take control," and "Taft to review plight of retarded in response to report on questionable deaths." [Internet Access: http://enquirer.com/mrdd/]

Service Employees International Union (SEIU)
Widespread Problems in Quality of Care
January 28, 2002

A new online service launched today provides important information for family members of people with mental retardation/developmental disabilities (MR/DD), advocates, state regulators and purchasers of MR/DD services. The service, http://www.rescarewatch.org, tracks issues regarding quality of care provided by ResCare, Inc., and its subsidiaries in the United States. The online service is not affiliated with ResCare, Inc. Copies of inspection and investigative reports for problem programs in California, Indiana and other states. [Internet Access: http://www.ctnow.com/news/specials]

Wisconsin
Milwaukee Journal Sentinel, January 25, 2002
Charges allege care center abused patients

A North Carolina-based corporation was charged in a groundbreaking prosecution Friday with 10 criminal counts alleging physical and sexual abuse of developmentally disabled patients at its care center in Milwaukee. Personnel at the Jackson Center Nursing Home, where "use of alcohol and drugs by staff" is a "regular" occurrence, were responsible for "numerous acts of abuse," ranging from ear twisting to forced hot sauce feeding to sexual assault on an elevator, the criminal complaint filed by the state attorney general's office charges. Neglect led to an unattended patient falling out a third floor window and another nearly drowning in a whirlpool, the complaint says. Benchmark Healthcare of Wisconsin Inc., was charged in the complaint with six counts of intentional abuse of a patient, three counts of intentional neglect of a patient and one count of second-degree sexual assault. The charges carry fines totaling up to $91,000. Assistant Attorney General William E. Hanrahan, who drafted the criminal complaint after an investigation by the Medicaid fraud control unit of the state Justice Department, said the unusual step of charging a corporation with crimes was taken because "the primary responsibility for the patients' care lies with the corporation." The facility in question is a large community-based facility. [Internet Access: http://www.jsonline.com/news/state/jan02/15528.asp]

Connecticut
Hartford Courant, December 2-4, 2001
Fatal Errors, Secret Deaths

Despite a history of official insistence that untimely deaths are virtually nonexistent in Connecticut's 774 group homes for people with mental retardation, a *Hartford Courant* investigation of group homes found evidence of neglect, staff error and other questionable circumstances in one out of every 10 deaths over the past decade. The series spans five articles, including "The Toll: Suffocation, Drowning, Choking and Burns," "How did they die? The State Won't Say," and "Lawmakers Call for Inquiry into DMR."
[Internet Access: http://www.ctnow.com/news/specials (link: Fatal Errors, Secret Deaths)]

Georgia
Atlanta Journal-Constitution, December 2-4, 2001
Dying in Darkness

At least 163 of Georgia's most vulnerable residents have died under the state's watch in the last four years, in circumstances largely shrouded in secrecy. Some who died were malnourished, bruised, scalded, and dehydrated. *The Journal-Constitution's* investigation into deaths of people with mental retardation began as an assignment to see how former residents of the Brook Run retardation center were faring after the facility closed in 1997. Many of the 60 families interviewed expressed concerns over injuries and deaths of residents who had been moved into smaller residential settings around the state. The Journal found that "Group home deaths reveal ugly picture of state care." The series spans 7 articles.
[Internet Access: http://www.accessatlanta.com/ajc/metro/brookrun/1202about.html]

National
Children and Family Research Center, November, 2001
Abuse of Developmentally-Disabled Children Bibliography

This resource lists 72 peer reviewed studies about the abuse of children with developmental disabilities (8 pages). [Internet Access: http://cfrcwww.social.uiuc.edu/respract/biblio.pdfs/abuseofdisabled.pdf].

Minnesota
Minneapolis Star Tribune, October 25-31, 2001
Voiceless and Vulnerable

Since 1995, at least 20 Minnesotans with mental retardation and other problems have died in cases in which maltreatment or questionable care was identified, a *Star Tribune* investigation found. The deaths involved neglect, starvation, physical restraint, medication overdose, drowning or other circumstances. At least 15 died in group homes where authorities or workers raised questions about proper training. The state's watchdog, the Office of the Ombudsman for Mental Health and Mental Retardation, has a backlog of about 500 deaths of mentally retarded and other vulnerable people that have yet to be reviewed. In addition, in 1994, the ombudsman stopped requiring intensive review of injuries, despite having broad authority to do so. More than 4,000 mentally retarded people have suffered serious injuries since then, the newspaper found. The injuries, which were reported to the ombudsman's office, ranged from serious head injuries to fractures to burns to frostbite. The number of serious-injury reports has increased each year since 1998, with 424 reported that fiscal year and 672 in fiscal year 2001. The Star Tribune's investigation provides the first public examination of deaths of mentally retarded people in Minnesota. Their files had been kept confidential by the ombudsman's office until the *Star Tribune* sued to have them opened. Three national experts reviewed death files for the *Star Tribune*. All three concur that Minnesota's system is broken, dangerous and operates with little accountability.

[Internet Access: http://www.startribune.com]
[Direct Internet access: http://www.startribune.com/stories/1600]

Pennsylvania Auditor General Audit, October 9, 2001
Casey audit finds serious deficiencies in state's oversight of Personal Care Homes; Offers over 30 recommendations to better protect residents' health and safety

The Pennsylvania Department of Public Welfare (DPW) was seriously deficient in its oversight of personal care homes, according to a performance audit released today by Auditor General Robert P. Casey, Jr. During the two-year period covered by Casey's audit, DPW renewed licenses without verifying that serious violations were corrected, licensed new homes without ensuring that administrators and staff were qualified, failed to impose fines and penalties as required by law, and investigated almost half of the complaints it received late. The commonwealth currently annually inspects about 1,900 personal care homes which, by definition, provide "safe, humane, comfortable and supportive residential settings" for older or disabled adults "who require assistance beyond the basic necessities of food and shelter but who do not need hospitalization or skilled or intermediate nursing care." In the two-year period covered by Casey's audit -- July 1, 1998, through June 30, 2000 -- bed capacity at Pennsylvania personal care homes increased 34 percent. During this time, however, DPW was not adequately staffed to oversee these homes. Casey's audit found that there were just 34 DPW employees monitoring more than 1,800 personal care homes with nearly 50,000 residents and a licensed capacity of nearly 75,000. [Internet Access: http://www.auditorgen.state.pa.us/Department/Press/PCH-PR.html]

Washington, D.C.
The Washington Post, September 9 - 12, 2001
The District's Lost Children

This four day investigative series (9 articles) reveals a decade of deadly mistakes that resulted in the deaths of 229 children from 1993 through 2000. One in five lost their lives after government workers failed to take key preventive action or placed children in unsafe homes or nursing homes. Seventeen of the deaths were homicides, most of them in homes. Many of these children were severely disabled. In the District, there are few long-term alternatives for severely disabled children whom nobody wants: some group homes, out-of-state institutions and foster homes.

Kansas
The Wichita Eagle, September 5, 2001
Malpractice verdict: $4 million

The family of a developmentally disabled woman who died in a western Kansas rehabilitation center won one of the state's biggest malpractice awards Tuesday: $4 million. The verdict included $2.5 million in punitive damages against Golden West Skill Center of Goodland and its parent company, Res-Care Kansas Inc. It was the largest jury award in Kansas for medical malpractice in three years, culminating an eight-week trial before U.S. Magistrate Judge John Reid at the federal courthouse in Wichita. The case involved the treatment of Christine Zellner, 23, of Denver, who died 13 days after entering the Goodland facility in January 1996. An autopsy never determined the cause of death, but the woman was found face down with marks on her wrist indicating she'd been tied up.

Wisconsin
The Milwaukee Journal, August 25 - 30, 2001
Caring for the Elderly, Disabled: Overwhelmed and Broken Down

A six-month examination of long-term care in Wisconsin finds caregivers overwhelmed, families torn apart and businesses barely surviving. The elderly and disabled wait interminably for care, and at times, they are harmed by the care they finally receive. And the future looks bleak.
[Internet Access: http://www.jsonline.com/news/state/aug01/care26082501a.asp]

The Tennessean, August 2, 2001
Tennessee may lose disability funding

Tennessee has failed to protect the health and welfare of people with mental retardation who live in supervised homes, a federal report has concluded. The federal government placed a moratorium on moving any more residents of state-run developmental centers into the community until the state takes "corrective action." Findings include, numerous medication errors; inappropriate medical care; many homes did not have adequate food supplies and/or the food in the homes was inappropriate for the clients' diets; staffers often have their children with them while on duty, even when clients' care plans indicate they should have (one-on-one) care; care plans are often outdated or not followed; and community agencies have refused to send records to family members, even when releases have been signed. The report also noted that substantiated cases of abuse and neglect have ranged from 25 incidents for every 100 individuals in homes in the community to 42 incidents per 100. In comparison, the rate for the state's developmental centers last year was 14 substantiated incidents of abuse or neglect for every 100 residents, according to a separate report released in January. The federal government began investigating last year after receiving complaints from family members that the state did not seem to be able to correct the problems.

[Internet Access: http://www.tennessean,com]
[Direct Access: http://www.tennessean.com/local/archives/01/04/07124262.shtml?Element_ID=7124262]
[See also: http://www.gomemphis.com/newca/local/080201/e2mental.htm]

Maryland
The Herald Mail, July 23, 2001
State reports cited agency for poor living conditions

The now defunct Hagerstown-based agency that served 25 developmentally disabled people last year received nearly 40 pages of citations from the state, some of which alleged poor living conditions, improperly trained staff and lack of medical supervision. The citations for Consumer Driven Services Inc. are listed in a 37-page May 2000 report put together by the state's Office of Health Care Quality. A 24-page follow-up report completed in December 2000 alleges that the agency did not fix many of the conditions for which it had been cited in the first report. The report states that many staff members of Consumer Driven Services were not properly trained in CPR, first aid and treatment for seizure disorders. An inspection of the group homes run by the agency turned up alleged safety and health hazards. An inspector of one of the homes wrote in the May report: "There is a strong smell of urine coming from one of the bedrooms that can be detected from the hallway. The bedroom bath has a very stained toilet and the shower door is broke. The cover is off the temperature control in the hallway. Curtains are off the window in one individual's bedroom and the dresser door swings open. A pot of stew, left over from the previous day, was found inside the oven." One of the visits by state officials in December found that the temperature in the living room and bedrooms in one of the homes was 55 degrees for several days. The reports also state that some of the group homes were understaffed, compromising the health and safety of the clients. Other pages of the reports detail instances in which one client had 12 to 15 teeth pulled by a dentist without first being told of the decision and another client was not being given doctor-ordered biweekly blood pressure checks. Consumer Driven Services had received state funding from the Western Region Developmental Disabilities Administration (DDA) until the local agency filed for bankruptcy on July 7. The DDA was the main funding source for the agency, contributing about $1.2 million toward the agency's annual budget.

[Internet Access: http://www.herald-mail.com]

[Direct Access: http://www.herald-mail.com/news/2001/07/23/local/State_reports_cited_age.html]

Illinois
The Arc of Illinois — Today, July 20, 2001
HCFA Comes Back to Illinois

In 1998, the Health Care Financing Administration (HCFA; now called Center for Medicare and Medicaid Services (CMS)) audited the Illinois home and community-based waiver. At that time CMS stated: "The review team found that the State is not in compliance with the statutory and regulatory requirements set forth to protect the health and welfare of waiver individuals and to safeguard the integrity of Federal funds expended. Illinois Department of Public Aid has not fulfilled its responsibilities to oversee the integrity of the programmatic and financial aspects of the waiver program. It has not adequately overseen Illinois Department of Human Services functions and activities by failing to perform evaluations of the waiver's implementation including program and fiscal integrity and accountability for both Federal and State funds expended by Public Aid." As a result of these findings, a moratorium was placed on new waiver placements and adult foster care was withdrawn from the waiver program.

The 2001 CMS audit of the Illinois waiver program will not find the Illinois waiver in jeopardy and will be less dramatic in its findings. Nonetheless, there continue to be serious problems that require attention in the following areas: Implementation of Program Plans; Inappropriate Use of Psychotropic Medications; High Case Loads; Ineffective Problem Resolution; Lack of Authority; Failure to Communicate with Co-Agencies; Lack of Freedom of Choice; and Placement in Restrictive Day Programs.

[Internet Access: http://www.thearcofil.org/newsletter]
[For 1998 CMS audit information see: http://www.thearcofil.org/newsletter/n121898.html]

Virginia
Times-Dispatch, July 19, 2001
Mental care crisis looming? Psychiatric-beds shortage worsening

Hospitals and rescue squads were forced to use a regionwide emergency plan for the first time this week to find beds for acutely ill psychiatric patients in the Richmond area. The decision to use the emergency diversion plan Monday was the latest sign of the worsening shortage of hospital beds for psychiatric patients since the closing of Capitol Medical Center in Richmond this month. "I wouldn't say it's a crisis, but it's on the verge of being a crisis," said Jon R. Donnelly, executive director of Old Dominion Emergency Medical Services Alliance, which helps coordinate operations between hospitals and rescue squads. The emergency plan was put into effect early Monday and ended late that night, but the loss of Capitol's 62 psychiatric beds continues to be felt by local hospitals and mental health agencies. Hospital emergency departments are seeing more people with psychiatric problems and being forced to hold them longer until a bed becomes available.
[Internet Access: http://www.timesdispatch.com] [Direct Link to Archives: http://www.archivesva.com]

California
The Center for Outcome Analysis, July 1, 2001
Eight Years Later: The Lives of People Who Moved From Institutions to Communities in California/Year 2001 Report of the Quality of Life Evaluation of People with Developmental Disabilities (The "Quality Tracking Project")

This report seeks to answer two questions, "Are the people who moved ("Movers") better off than they were when living in Developmental Centers?" and "Are the people who moved into community homes better off than they were last year? (do they continue to grow, learn and flourish year after year in the community?).

The report finds that Movers are generally better off in 11 of the 21 "dimensions." The report notes that the Movers are somewhat worse off in the "number of close friends," the "staff perceptions of the quality of health care," the "frequency of dental care," and the opportunity for supportive and competitive employment. Researchers also found, however, that the average Mover lost ground in adaptive behavior in the past year in the community. The average Mover also lost ground in the challenging behavior area; that is, their challenging behavior increased. The researchers noted, "This is the first time in 22 years of constant research by this team that such an outcome has been observed. We have never before seen people in community service systems lose skills and increase challenging behavior. However, the monitoring process put into place through Welfare & Institutions Code 4418.1 has resulted in early detection of these problems. A concerted effort to identify the reasons for these outcomes can surely result in quick and decisive action to arrest further decline. Without the kind of quantitative monitoring mandated by the Legislature for the present project, no one would even know that the average Mover has now begun to lose ground behaviorally." Researchers attribute the decline, in part, to an underfunded community system.

Office of Inspector General, U.S. Department of Health and Human Services
May 3, 2001
Reporting Abuses of Persons with Disabilities

Federal requirements for protecting persons with disabilities from abuse and neglect are directed at facility providers rather than State agencies. Some persons with disabilities reside in facilities that are subject to the Health Care Financing Administration's (HCFA) conditions of participation as well as State laws and regulations. However, we estimated that up to 90 percent of persons with disabilities reside in facilities, such as group homes, some residential schools, and supervised apartments, that do not receive HCFA funds or were not part of the Medicaid waiver program and rely solely on various levels of protections that are provided by State laws and regulations. In addition, Department of Health and Human Services (HHS) is at a disadvantage in identifying systemic problems since it receives incident information from a limited number of sources.

We recommend that HCFA, the Administration for Children and Families, the Substance and Mental Health Services Administration, and the Food and Drug Administration work cooperatively to provide information and technical assistance to States that would (1) improve the reporting of potential abuse or neglect of persons with disabilities; (2) strengthen investigative and resolution processes; (3) facilitate the analysis of incident data to identify trends indicative of systemic problems; and (4) identify the nature and cause of incidents to prevent future abuse. [Internet Access: http://oig.hhs.gov/oas/reports/region1/10002502.htm]

Missouri
Missouri Office of State Auditor, March 15, 2001

Missourians with developmental disabilities who rely on contractor-operated facilities are not well protected from acts of physical aggression by other clients or from medication errors. Inadequate monitoring by the states 11 regional centers over contractor-operated facilities, which provide day programs and residential environments to nearly 9,000 developmentally disabled, leave clients and staff at risk. The review included an analysis of incident and injury reports of eight contractors operating in five of the states regional centers. [Internet Access: http://www.auditor.state.mo.us/press/2001-20.htm]

Wisconsin
The Milwaukee Journal, February 21, 2001
Inspector falsified reports on care sites, officials say; Misconduct charges sought amid state report alleging 'pattern of lying'

A state inspector responsible for monitoring the care of frail elderly and disabled clients in more than 100 assisted living homes is accused of falsifying reports to show some homes were problem free when, in fact, he

had not visited them for years. "There . . . were ample indications that the employee's performance had not been adequate for a significant period of time," Patrick W. Cooper, director of the state Office of Program Review and Audit, wrote in a cover letter to the report. "The employee wrote only 11 statements of deficiency over an almost four-year period, when a typical licensing specialist might have written between 150 and 200. "The employee's work was also subject to many complaints by external parties, yet these complaints were not acted on in a manner that would lead to uncovering the extensive misrepresentation of work activities. . . . We believe he showed a pattern of lying about having completed licensing and complaint investigation work that he, in fact, had not performed." [Internet Access: http://www.jsonline.com/news/metro/feb01/inspect21022001a.asp]

Texas
WFAA-TV (Dallas News 8), February 8, 2001
News 8 investigates ResCare Part II

[Transcript excerpts] "Thirty years ago, a process began in this country to stop warehousing people with mental retardation in state institutions and move them out into community-based group homes. The theory was that by deinstitutionalizing people with mental retardation, we would give them better, more normal lives. ResCare is the largest provider of group homes in Texas and the nation. In Texas, many people may know ResCare as EduCare, because the two firms merged about two years ago. Together they operate more than 170 group homes around the state. No one else comes close in sheer volume of clients or revenue. It's become a multi-billion dollar business, which has some asking why the company only allocates $5 per day per person to feed their mentally retarded clients . . ."

"According to ResCare, the amount [$5 per day] is an 'acceptable and widely used rule of thumb for a daily food budget' and 'falls within the official guidelines available from (USDA).' But a 1995 study which specifically compares 700 group homes in Texas shows that even six years ago, the average daily allotment for food was $5.86 per person. The study was provided by ResCare's own paid consultant . . . Today, criticism of ResCare's treatment of their mentally retarded clients extends beyond just food and the borders of Texas. The company has come under fire in Florida, Indiana and New Mexico, where there is a moratorium on placing any new residents in ResCare facilities because of serious health and safety issues . . . But what concerns advocates for the mentally retarded is that despite numerous warning signs over the years, state regulators have continued to let ResCare expand — to the point that even if regulators needed to close ResCare's facilities, there wouldn't be enough other group homes to take in their clients."

Washington
Washington State Internal Audit, December 2000

An internal, simulated audit of the DSHS Division of Developmental Disabilities (DDD) Community Alternatives Program (CAP) Medicaid Home and Community-based Services (HCBS) Waiver was conducted to identify potential problems when the program receives its next formal audit by the Federal Health Care Financing Administration (HCFA). The audit of the $200 million state program for the developmentally disabled found that the program is so "woefully inadequate" that it poses a threat to the very health and safety of the 10,000 people it serves. Federal officials "would likely conclude that the lack of sufficient personnel and resources creates a situation in which no one is fully aware of what is happening to the average developmentally disabled client," the report reads. "Case management oversight and monitoring of individuals is so limited as to pose high risks for the individuals being served."
[Internet Access: http://www.wa.gov/dshs/geninfo/simaud.html].

Connecticut
The Connecticut Post, December 22, 2000
Group homes need uniform safety rules

Advocates for the disabled and the State Department of Mental Retardation want to know whether two drownings at Connecticut group homes for people with mental retardation, being similar and occurring close together, indicate a widespread problem. The Department of Mental Retardation will investigate whether the drownings were isolated incidents or part of a pattern of neglect.

[Internet Access: http://www.connpost.com/]
[Direct Link: http://www.connpost.com/S-ASP-Bin/ContentFrmBldr.asp?PUID=6747]

Pennsylvania
The Post-Gazette, September 29, 2000
Retarded man drowns in group home; was moved from Western Center in May

The state Department of Public Welfare will launch an investigation into the death, said Jay Pagni, a spokesman. The parents' group that fought the closing of Western Center have tabulated that 23 mentally handicapped people have died from accidents in group homes since they were taken out of Western Center. In 1998, the state decided to close Western Center and move its remaining 380 residents to group homes. State Auditor General Bob Casey Jr. released a 162-page audit in May that criticized state welfare officials for being too lax, too slow, and too ineffective in ensuring the safety of mentally retarded individuals living in group homes. [Internet Access: http://www.post-gazette.com/neigh%5Fsouth/20000929barber2.asp]

Maine
Maine Sun Journal, July 23, 2000
Institution gets new lease on life

It is what was best about Pineland, an institution that closed in 1996, that captured the imagination of Owen Wells who heads the Libra Foundation. "I found [Pineland] had spectacular potential," he says. "How better to meet the needs of the disabled people, both physically and mentally, here in Maine?"

Wells pictures a multi-use complex that would draw tenants from all walks of life, including white- and blue-collar businesses, accommodating all handicaps. It would mix business, industry, recreation and education. His picture is set out in blueprints, approved by town and state officials. In December, he signed a purchase agreement for the property. The deal closed last month with Libra paying $200,000 for the campus and $540,000 more for an additional 617 acres abutting the former school. Estimates for the completed project top $40 million.

Rather than running from its controversial past, Wells chose instead to embrace it. "I thought there's nothing to be ashamed of in terms of what Pineland was for many years. It was a wonderful farm operation and it was a wonderful facility," he says. He's even commissioned a book about Pineland's 88 years as an institution. "We set out very early not to abandon the history," Well says. "The history is good. We think it is a history that ought to be acknowledged."

Texas
Austin American-Statesman, May 31, 2000
Hard questions about their care

Between March 1999 and last April, Texas withheld Medicaid money from at least 104 group homes for health and safety violations. Unless there is a complaint, Texas conducts annual surprise inspections of its 11 state schools and 890 group homes with six or more residents. It surveys the providers of more than 200 smaller homes but doesn't inspect them. Most of the money was withheld from group homes because of minor infractions, but there also were about a dozen more serious cases of abuse and neglect. Texas will have to make a much bigger commitment than it's making to properly move to a community-based system. Compared to other states, Texas allocates little money for Medicaid, the joint state-federal program that pays for much of the care

in any setting. In 1998, Texas was 41rst in total spending. It was 40th in community-care spending and 29th in institutional spending. Texas' relative stinginess may have contributed to some of the health and safety violations in the state schools and group homes. Many of the incidents were related to a lack of supervision. With an entry-level, direct care job at Austin State School paying just $7.26 an hour — about 50 cents more than the starting salary at McDonald's — state schools and group homes have trouble attracting and keeping staff. [Internet Access: http://archives.statesman.com]

The American Prospect, Volume 11, No 12, May 8, 2000
Neglect for Sale

Two decades ago, advocates fought to shut down abusive institutions that warehoused the mentally retarded. Today, people with developmental disabilities face a new threat: big business. The American Prospect offers an investigative report by Eyal Press and Jennifer Washburn which looks at ResCare, the nation's largest for-profit provider of services to people with developmental disabilities.

[Internet Access: http://www.prospect.org - link: Archives (search by author -- Eyal Press]
[Direct Link: http://www.prospect.org/print/V11/12/press-e.html]

Pennsylvania
Pennsylvania Auditor General Audit, May 8, 2000
Audit finds serious deficiencies in Ridge administration's oversight of group homes; Casey offers nearly 50 recommendations to improve quality of care

A performance audit of the Commonwealth's oversight of group homes for the mentally retarded in western Pennsylvania has found serious deficiencies that threaten the health and safety of residents, including allegations of abuse and unexpected deaths that were not investigated promptly, direct care workers with criminal backgrounds, and inadequately trained caregivers. In addition to numerous audit findings, Pennsylvania Auditor General Robert P. Casey, Jr.'s audit report offers 47 recommendations to improve the Ridge administration's oversight of group homes and, ultimately, the quality of care provided to group home residents across Pennsylvania. Casey's audit, which examined the Pennsylvania Department of Public Welfare's (DPW) oversight of eight group homes in Allegheny, Beaver, Fayette, Washington, and Westmoreland counties from July 1, 1994, through June 30, 1999, focused on four areas: 1) unexpected deaths and incidents of abuse; 2) staffing issues that affect the health and welfare of group home residents; 3) the quality of service provided to residents; and 4) the physical condition of the group homes.
[Internet Access: http://www.auditorgen.state.pa.us/Department/Press/grouphom.html]

Pennsylvania
Post-Gazette, April 12, 2000
State closing home for mentally retarded amid continued appeals, protests

State officials said they would begin to shut down Western Center in Canonsburg today, an announcement that prompted last-minute court appeals, protests from parents and the near arrest of a mentally retarded resident after a confrontation with state police. As final preparations were made for the closing, the center operated more like a fortress than a home for the mentally retarded. State police set up a roadblock behind the administrative building yesterday so relatives could not visit residents until they were moved to other facilities.

New Mexico
Albuquerque Journal, April 9, 2000
Troubled Care: Assisted Living Provider Faces Lawsuit, Complaints, Moratorium on New Clients

On April 9, 2000, the *Albuquerque Journal* reported that ResCare New Mexico, which receives $10 to $12 million a year from the health department to serve its citizens with mental retardation and developmental disabilities, has been hit with a number of allegations of neglect and abuse over the past year. ResCare and its subsidiaries in New Mexico have the highest rate of abuse at about 18 cases of abuse per 100 clients; they are also one of the largest community-based providers. A lawsuit has been filed against ResCare alleging a pattern and practice of abuse and neglect; Arc of New Mexico, which serves as guardian for 153 people, will be moving all of its wards from ResCare homes; The Arc is threatening to file a lawsuit against ResCare; and their is a moratorium on new placements in ResCare programs. New Mexico closed its last state-operated developmental center in 1997, following a lawsuit by Protection and Advocacy.
[Internet Access: www.abqjournal.com]

Washington State
Seattle Times, March 24, 2000
Record verdict against state in abuse case

The state Department of Social and Health Services and two adult family-home operators were ordered by a jury to pay $17.8 million - the largest judgment ever against the state - to three disabled men who say they were molested in the state-licensed facility. The size of the judgment from the Pierce County Superior Court jury shocked officials from the governor's office, DSHS and the Attorney General's Office, the agency that defended the state in the suit. The case has major implications for the future: At least a half-dozen other defendants abused or neglected in long-term care claim they could have been saved from suffering if the state had acted properly. These and other cases were highlighted in a Seattle Times investigation last year that concluded the state did little or nothing to stop abuse or neglect of people in state-licensed care, nor did it often prosecute their abusers.

Oregon
Oregon Statesman Journal, March 12 - March 15, 2000
Fairview's Legacy

(1) Sunday, March 12, 2000: Day 1: Success and Failure

- (a) Safety of disabled in doubt after deaths
- (b) Inquiries find neglect a key factor
- (c) Fairview history: Dignity wins out over time
- (d) High turnover, heavy caseload plague system
- (e) Homes that work: Group Home (Shangri-La) rebounds from bleak times
- (f) Salem group home fell into dysfunction

(2) Monday, March 13, 2000: Day 2: Comparing Services

- (a) 4,000 disabled wait for state aid
- (b) Waiting list can seem endless
- (c) Fairview's end won't shorten list
- (d) Past residents: Change can be difficult
- (e) Other states face lawsuits
- (f) Views on group homes varied:
  - Group home gets praise from mother
  - Father hopes to see end to group homes
  - Leaving Fairview a mistake: Brothers go without therapy
- (g) Individual choice is the main advantage

(3) Tuesday, March 14, 2000: Day 3: Market Shifts

(a) Caregivers fight to remain solvent
(b) Group home boom: Turnover, funding still worrisome
(c) Workers face high demands
(d) Rising costs hit care provider
(e) Experiences of area facilities show challenges facing industry
(f) Low pay fuels staff turnover
(g) Group homes draw complaints
(h) Following Fairview's former employees: Many still caregivers; some rebuild careers

(4) Wednesday, March 15, 2000: Day 4: Looking Ahead

(a) Costs likely to delay developing campus
(b) Plot offers great variety of options
(c) Saving old sites possible
(d) Officials, residents plan for Fairview's future
(e) Fairview land use complicated issue
(f) Mothballing costs remain uncertain
(g) Buildings hard to save or sell
(h) Industry likely to replace farm

[Internet Access: www.statesmanjournal.com]
[Direct Link: http://online.statesmanjournal.com/special_section.cfm?i=1007]

Oregon
The Oregonian, January 7, 2000
State inquiry finds neglect of former Fairview resident

A longtime Fairview Training Center resident who died less than two months after moving into a group home in Salem was neglected by his new caregivers, and public officials who learned of the neglect failed to act, according to a state investigation released Thursday. The report from the Office of Client Rights concluded that neglect led to dehydration and malnourishment in the weeks before his death and that a number of public officials and Salem Hospital failed to report his condition or investigate as required by law. Gary Avery's death has heightened concern about how Fairview's former residents are faring in a community system plagued by high turnover of workers and relatively low wages. To make sure no similar problems exist, the state's Development Disability Services Division is reviewing the cases of 260 other former residents who have been moved into the community since May 1998. Fairview is scheduled to close in late-February.

[Internet Access: http://www.oregonlive.com/search/oregonian]

Washington, D.C.
Washington Post, December 1999 - January 2000
Invisible Deaths: The Fatal Neglect of D.C.'s Retarded

(1) System Loses Lives and Trust, December 5, 1999
(2) D.C. Vows Review of Deaths in Homes, December 6, 1999
(3) City to Investigate Deaths, Williams Promises Accountability, December 7, 1999
(4) D.C. Official Suspended in Probe of Homes, Records of Deaths Allegedly Shredded December 9, 1999

(5) Files on Retarded Out of Reach, Advocates Frustrated by Lack of Cooperation from D.C. Superior Court, December 15, 1999
(6) Group Home Administrator Named, December 20, 1999
(7) Group Home Deaths, Washington Post Editorial, January 10, 2000

Note: There has been significant follow-up since the investigative series by *The Washington Post* (see e.g., "Progress Reported On Care of Retarded," September 26, 2000; "Group Homes' Dept to D.C.: $6.8 Million," October 27, 2000; and "District Settles Claims for Retarded, Agreement Includes $29 Million Fund," January 23, 2001).

Pennsylvania
A disabled boy, a family in crisis: Mounting pressures may have led a couple to abandon their child, December 1999

Extensive national news media coverage has been available about the crisis facing Dawn and Richard Kelso. The couple has been charged with "abandoning" Steven, their 10-year old son with severe developmental disabilities, at the hospital that had previously served Steven's extensive health care needs. In December, 1999 Mrs. Kelso retired as a member of the Pennsylvania DD Council; Mr. Kelso is the CEO of a Fortune 500 company.

[Internet Access: http://www.phillynews.com (news archives search link - keyword: kelsos)]

Washington, D.C.
Washington Post, March - May, 1999
Invisible Lives: D.C.'s Troubled System for the Retarded

(1) Forest Haven is Gone, But the Agony Remains, March 14, 1999
(2) Olympic Achievements Out of Reach, March 14, 1999
(3) Elaborate Structure of Care, March 14, 1999
(4) Residents Languish, Profiteers Flourish, March 15, 1999
(5) Nonprofits Struggle in Current of Greed, March 15, 1999
(6) Death Among the Mentally Retarded, March 15, 1999
(7) U.S. Probes D.C. Group Homes, May 4, 1999

[Internet Access: http://washingtonpost.com/invisible]

Georgia
The Atlanta Constitution Journal, February 20, 1999

In February 1999, three former employees of the Northeast Georgia Community Service Board, which provides social services in a 10-county area, were charged with insurance fraud, theft by deception and conspiracy to commit theft by deception. The three were among nine employees fired on April 1, 1998, after an investigation into allegations of insurance fraud, abuse and neglect involving people with mental retardation. The former employees allegedly sold life insurance policies to the individuals with mental retardation and listed themselves as beneficiaries. Health care officials have said the situation represents one of the worst cases of systemic abuse of clients in Georgia in years. Investigators painted a picture of a community care network apparently operating with almost no oversight. An audit into nine of the 28 community service boards in Georgia was ordered. A preliminary draft reveals a system that lacks oversight and financial accountability and one in which officials manipulate treatment and billing practices to increase Medicaid payments (Source: ***The Atlanta Journal Constitution***, February 20, 1999).

California
San Francisco Chronicle, February, 1997 - August, 1998

Fifty-six (56) articles were released detailing the abuse, neglect and death that plagued California's system of community-based care for people with mental retardation following the aggressive deinstitutionalization of over 2,000 people. The articles include reference to University peer-reviewed research that finds risk of mortality to be higher in California community-based programs than in the state institutions serving people with mental retardation.

The California mortality studies can be accessed on the Internet at http://www.LifeExpectancy.com, link: articles (comparative mortality studies).

[Internet Access: http://www.psych-health.com ("developmental disabilities" link, then years 1997 and 1998) or http://www.sfgate.com/chronicle (search link - key words Lempinen and disability).

Pennsylvania
The Philadelphia Inquirer, November 1997
Lawsuit without an End

(1) Serving the Retarded: Some are more equal: Those who once endured a notorious institution get a cornucopia of care in Philadelphia. But others, in the arms of their families struggle. And wait. November 2, 1997.

(2) Case studies tell a tale of disparity: Two men from Pennhurst exemplify the strides taken on their behalf. And then there's Denise Carruth. November 3, 1997.

(3) Lawsuit aids some retarded at all costs: The rights of Pennhurst's alumni have been well guarded for years. But amid bounty, some feel forsaken. November 4, 1997.

[Internet Access: http://www.phillynews.com (news archives search link - keyword: pennhurst)]