

VOICE OF THE CONSUMER

Adult Home Residents Speak Out

In 2002, when Clifford Levy of the New York Times wrote his Pulitzer Prize-winning expose of the Adult Home system, the general public was shocked. Politicians reacted with outrage and calls for reform.

One group, however, was not shocked at all, because it knew all too well the plight of 12,000 New Yorkers with mental disabilities living in Adult Homes. Residents, themselves, had long been struggling to improve their care, both systemically and in their own individual Adult Homes.

The Coalition of Institutionalized Aged and Disabled (CIAD) is the primary vehicle through which Adult Home residents advocate on their own behalf. Founded in 1973 to be a voice for nursing home residents, CIAD has increasingly turned its attention to Adult Homes over the years.

CIAD members point to many types of problems within the Adult Home system. However it is the underlying issues of isolation, hopelessness and sustained dependence which are most devastating to residents. Too often, it is this sense of helplessness that allows operators to offer only inadequate medical and mental health care, bad food and poor housing.

"We are very much unknown and ghettoized," says Irene Kaplan, a CIAD board member and resident of the Surf Manor Home in Brooklyn. "Once you come into an adult home, for the most part you are not encouraged to move forward. In many cases it is discouraged. Intimidation is often used."

CIAD works to assist residents find their own voice with which to advocate for their needs and services – on both a micro and macro level.

"In individual adult homes, Resident Councils have developed as a means of helping residents maintain as much control over their lives as possible," says Geoff Lieberman, CIAD's Executive Director. "They provide a democratic vehicle for resolving complaints and a means for people to get together and talk about their concerns and issues."

However, developing a successful Resident Council is not always easy, particularly in adult homes where some owner operators either openly resist or subvert the process. "In some cases they are quite effective," says Kaplan. "In others, the residents are so intimidated or so ignorant that they won't support it. In many cases, the Resident Councils are operated by the owners."

CIAD provides technical assistance to the individual Resident Councils in the various homes. "We help people to organize and strengthen their Resident Council so they can be as effective as we think they can be," says Lieberman.

Residents point to cases where Resident Councils have been able to address concerns and issues at individual adult homes, ranging from food to telephone access. At Madison-York Adult Home in Rego Park, a Resident Council got 56 signatures on a petition complaining about stale bread, says CIAD member Dorothy Harle.

In some cases, individual Resident Councils have undertaken projects with systemwide implications. The Resident Council at Sanford Home in Flushing Queens, led by Ray Harris advocated to ob-

tain MTA Half-Fare cards for disabled residents. The effort was so successful that CIAD picked it up as a project and worked with Resident Councils across the City to help more than 450 residents apply for half-fare cards.

CIAD partners with MFY Legal Service's Adult Home Advocacy Project in monitoring adult homes that house large numbers of mentally disabled adults. "We provide training to residents on their rights and meet with them at the homes to discuss and address complaints and legal issues," says Lycette Nelson, a MFY Staff Attorney with the project.

CIAD handles complaints that do not require legal expertise, while MFY works with the residents who have legal issues, providing advice and counsel, brief services, and full representation as needed. "Over the past year we have handled over 200 individual cases of adult home residents," says Nelson. "These cases involved the withholding or misuse of resident funds; refusal to re-admit a resident after a hospitalization; and violation of residents' civil rights."

"For many years, CIAD and MFY Legal Services have been the only organizations regularly walking through the doors of adult homes," says Lieberman. Last year, CIAD's three-member staff made 327 visits to 35 adult homes in New York City.

On a system-wide basis, CIAD members have taken their case to Albany to advocate for a variety of causes. Last year, they held a CIAD Speak-Out to remind politicians that Adult Homes are still a system which needs fixing. Another Speak Out is scheduled this month. The issues, unfortunately, haven't changed.

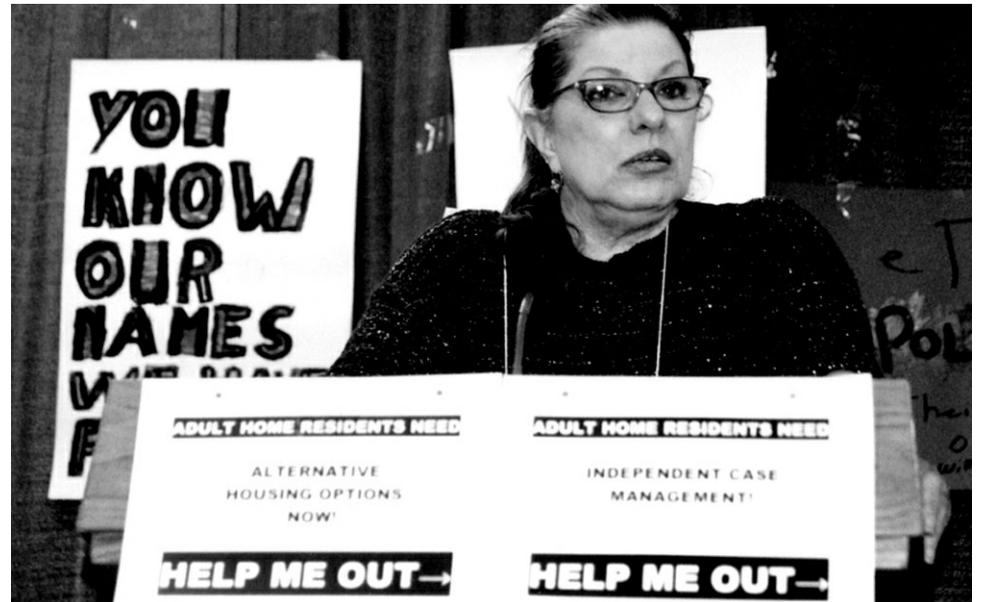
Last year, Governor Pataki vetoed an \$11 increase in the SSI Personal Needs Allowance. "Right now it is \$130 per month or \$150 for those with SSI-D," says Gerard Heller, a resident at Surf Manor. "Is that money to live on? When we go up to Albany, we are going to tell legislators to amend bill A-238 so we can have an increase in our allowance." Heller and the other CIAD members are also seeking a separate temporary clothing allowance.

CIAD also wants improved health and mental health care and air conditioning in rooms. Levy's Times series cited cases of residents literally dying from the stifling heat in Adult Home bedrooms. "I have told our operators that air conditioning would be cheaper for the public rather than having residents going to hospital emergency rooms," says Kerry O'Day.

Most importantly, CIAD wants alternatives to the Adult Home system itself.

"Adult homes were originally supposed to be a solution for the elderly; those who needed daily assistance rather than serious mental health care," says Kaplan. "What has happened over time is that adult homes have become catch-alls for anyone and everyone with any kind of disability, whether it be psychological or physiological."

"One size fits all," is how CIAD characterizes this fundamental problem. "Not everyone living in an adult home should be there," says Gary Levin, a resident of Ocean House in Far Rockaway and a member of CIAD's Policy Committee. "It is a dead end for some people and dead ends are not good."



Irene Kaplan, a CIAD Board Member and resident of Surf Manor Adult Home, advocated the residents' agenda in Albany.

MFY Legal Services has taken this position to court by working to file *Disability Advocates v. Pataki et al*, which argues that placing mentally ill adults in large adult homes is a form of re-institutionalization prohibited by the federal Americans with Disabilities Act.

Advocating for themselves is already a success for many CIAD members. "The

system leaves a lot to be desired, but if you are active and speak out, they will make changes," says Robin Stigliano, a resident of Bay View Manor in Bensonhurst. "That is what CIAD taught me. Before, I was just part of the flock. Now, I help out."

For information go to www.ciadny.org or call 212-481-7572.

South Brooklyn Legal Services' Housing Advocacy Project

advocates on behalf of parents whose children remain in foster care due to the lack of adequate housing. The project trains case workers and lawyers who work with families involved in the foster care system on how to help clients with housing problems. We also speak to groups of parents, and provide advocacy and representation to individual parents. We assist parents in accessing housing subsidies and, where necessary, the City's family shelter system. We serve parents in all 5 boroughs.

For more information or to schedule a training, contact

Jessica Marcus at (718) 246-3260 or e-mail jessicam@sbls.org.

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