

A SUCCESSFUL LIFE IN THE COMMUNITY AFTER LONG-TERM INSTITUTIONALIZATION

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In this newsletter, we are honored to be able to share **Irene Kaplan's** story.

In Short

After spending sixteen years living at an adult home in New York, Irene Kaplan says she would not wish a similar experience on her worst enemy. For Irene, the environment in the home was one of intimidation, mistreatment, and loss of control. She felt the staff treated her like a child, inculcated a feeling of dependency, and imposed an “artificial system” for when and how to carry out everyday tasks. Nevertheless, now that she again lives independently in her own apartment, she has succeeded in regaining her ability to live her life as she chooses. Since she left the adult home in 2009, Irene has dedicated herself to reforming the state’s mental health system to ensure that no one has to live in an adult home unless it is their own choice.

Life Before

Irene entered the adult home system out of desperation and a lack of alternatives. She had lost her apartment and was experiencing a period of homelessness and illness. During her time on the streets, she suffered a series of respiratory infections and was robbed of her Social Security Insurance checks. Compared to her life on the streets, a short

stay at the adult home seemed to guarantee at least that she would have shelter, regular meals, and access to her SSI benefits.

Even as she moved into the adult home, though, Irene knew that securing these comforts would entail tradeoffs. The quality of the food was, in her opinion, “lousy” compared to her own cooking, and she sacrificed the ability to decide what to eat. She did not observe any effort by the staff to take into account the nutritional needs of individual residents, many of whom had health conditions such as diabetes, food allergies, or, like Irene, high cholesterol. The residents were unable to choose healthier meal options that would have helped them to manage these health concerns.

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Irene had to cede control over her surroundings and her roommates. Irene says one roommate physically assaulted her. Another was a “hothouse blossom” who

insisted on keeping the bedroom very warm and prevented Irene from opening a window to let fresh air into the room. This roommate also snored, causing Irene to lie awake at night and sleep only during the day.

Irene wanted to move into her own apartment because in the home “everything was done for me, but not to my satisfaction.” The staff applied the same rules to all residents. For example, even though Irene regularly left the home to visit her doctor and pharmacy, she was not free to come and go as she pleased: if she returned late, the door would be locked and she would have to wait for a staff member to come let her in. It took three months and legal intervention before Irene could install a personal landline in her room as an alternative to going through the home’s switchboard.

What Helped Irene

A few years after she moved into the adult home, Irene was approached by a member of the Coalition of Institutionalized Aged and Disabled (CIAD), a consumer-led organization that advocates for the rights of individuals living in nursing homes and adult homes. The advocate’s message of independence and self-advocacy strengthened Irene’s conviction that she could one day return to an independent life in the community.

Irene spoke out against the state’s mental health system, which in her view operated the adult homes as a “dumping ground for unwanted people” whose families could no longer care for them. Irene proudly testified during the trial in *Disability Advocates Inc. v. Paterson*, the landmark *Olmstead* case that reformed New York’s mental health system to ensure the availability of community-based services for adults with mental illness. During her testimony, when the judge asked

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While the *Disability Advocates* case was pending, New York created a small program to provide supported housing to 60 people living in adult homes. As a result, sixteen years after she had entered the home, Irene was finally able to move into an apartment in Brooklyn through this program. She was able to choose an apartment with a location that she felt provided safety and convenience. Irene also liked the unit itself, which felt airy and quiet and offered views of greenery and the sky through the windows.

Irene has been able to organize her apartment as she wished. She was pleased to have the space to expand her book collection beyond what she had been able to keep in the adult home. She also enjoys the peace of living alone with her cat, with few distractions while she reads or watches television – a strong contrast to the frequent interruptions at the adult home.

She also used her transition as a motivation to stop smoking: in fulfillment of her promise to herself that she would quit smoking when she left the adult home, she smoked her last cigarette the day she moved into her apartment.

For Irene, it was easy to resume her familiar routines in the community. Even though her experiences in the adult home had sapped her self-confidence, she was comfortable shopping and cooking for herself again within a few days of her move into her own apartment. She values the ability to decide for herself what to prepare for each meal – whether it will be steak, chicken, or simply a bowl of cereal.

Although she hadn't known the area well before she moved in, she quickly grew to like her new neighborhood. She has also enjoyed getting to know her neighbors, who are always eager to hold the door or lend a hand when they see Irene with her walker. One of Irene's neighbors is also a former adult home resident, and Irene has enjoyed the freedom to speak and joke freely with her neighbor about their shared experiences, which the women were reluctant to do while they were living in the home.

She feels lucky that everything she needs is a short walk away from her apartment, including a medical clinic across the street and her eye doctor around the corner. She is glad to have the opportunity to make her own decisions about where to go for everything from medical care to shopping. A home health aide comes to help her with laundry, deliver groceries, pick up her prescriptions, and perform other tasks around her apartment that are difficult for Irene because of her mobility issues.

Irene has also regained the ability to control her own finances. During her time in the adult home, she received only a small allowance of a little over a hundred dollars a month, much of which she spent on snacks and meals when she didn't like the home's offerings. Now she can spend her money as she finds appropriate. She has enjoyed having the means to acquire some furnishings for her apartment, many more books, a television,

and a second-hand computer and tablet that have provided access to the Internet. She also used her transition as a motivation to stop smoking: in fulfillment of her promise to herself that she would quit smoking when she left the adult home, she smoked her last cigarette the day she moved into her apartment.

Irene's Life Today

Irene has continued her advocacy work with CIAD to this day. She has found a sense of purpose in her role as a peer advisor, which allows her to educate adult home resident about their rights. She has also traveled to the state capital to meet with legislators and raise awareness about the adult home system. Her message to lawmakers is clear: “the adult home system is not a place to spend the rest of your life unless you choose it for yourself.” Irene tells decision makers that the state's mental health system needs to be revamped to provide people with more choices and the supports they need to remain in their own homes in the community. CIAD, she says, “gets things done” through their advocacy and outreach work. After experiencing a loss of control and independence during her years in the adult home, this ability to pursue systemic change is invaluable to Irene.

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