

# L10-235-cv (L)

10-251-cv, 10-767-cv, 10-1190-cv (CONSOLIDATED)

IN THE  
**United States Court of Appeals**  
FOR THE SECOND CIRCUIT

DISABILITY ADVOCATES, INC. AND UNITED STATES OF AMERICA.,

*Plaintiffs-Appellees,*

— v. —

NEW YORK COALITION FOR QUALITY ASSISTED LIVING, INC.,

*Movants-Appellants.*

— and —

DAVID A. PATERSON, ET AL.,

*Defendants-Appellants.*

ON APPEAL FROM THE UNITED STATES DISTRICT COURT  
FOR THE EASTERN DISTRICT OF NEW YORK, CIVIL NO. 03-3209

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**BRIEF OF C.C., I.K., P.S., G.L. AND 13 OTHER CURRENT AND  
FORMER RESIDENTS OF ADULT HOMES, AS *AMICI CURIAE* IN  
SUPPORT OF AFFIRMANCE AND PLAINTIFFS – APPELLEES,  
DISABILITY ADVOCATES, INC.**

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## INTEREST OF AMICI CURIAE

The 17 individual *amici* joining this brief are current and former residents of adult home institutions in New York. Some moved to independent supported housing when the State made 60 apartments available to the 4300 people with mental illnesses living in adult homes in the City. Others still live in adult home institutions, but desperately want to leave and move to their own apartments if the State makes supported housing available. These individual *amici* will directly benefit if this Court affirms the trial court's decision.<sup>1</sup>

## SUMMARY OF ARGUMENT

C.C., I.K., P.S., G.L., and the other individual *amici* have joined this brief to tell the Court their own stories. They describe their daily lives, and what it will mean to them if this Court affirms the trial court. They describe what it is like to live in adult homes. They are “warehoused,” treated like children, deprived of privacy, isolated from and stigmatized by the community, confined to strict and numbing institutional routines (sometimes spending hours in line for medication and meals every day), and even threatened with retaliation if they try to protest such conditions. The few lucky residents who already have moved to supported

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<sup>1</sup> All parties have consented to the filing of this brief. No counsel to a party authored this brief in whole or in part. No party contributed money to fund preparing or submitting this brief.

housing describe the transformation in their lives. They talk about their new-found freedom, privacy, and autonomy with respect to daily life. Now they can do the things that people who don't live in institutions take for granted every day, like being able to have hot buttered toast and a cup of coffee when they want one, to cook and eat healthy meals of their choosing, to live alone or with roommates they have chosen, to talk with and entertain friends and relatives in privacy, and simply to control the day-to-day details of their lives. They discuss the ability to control their own finances and medication, their improved integration into the community, and being relieved of the constant and automatic stigma and disdain from neighbors that comes with living in the local adult home. As C.C. says,

There's nothing like having your privacy, and being able to go to bed and wake up when you feel like it or when you need to. Not to be regimented like you are in the army, and to eat what you want when you want it. That feeling of freedom is one of the greatest feelings in the world.... I can't tell you the number of days I have woken up and I think of [life in the adult home] like it was a bad dream.<sup>2</sup>

The *amici* still in adult homes talk about similar improvements they believe a move to supported housing would bring to their lives and health.

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<sup>2</sup> C.C. Interview 9/27/10.

## ARGUMENT

### **I. PEOPLE WITH MENTAL ILLNESSES WHO MOVE TO SUPPORTED HOUSING REPORT SUBSTANTIAL IMPROVEMENTS IN QUALITY OF LIFE, HEALTH, WELL-BEING, RELIEF FROM STIGMATIZATION, AND INTEGRATION INTO THE COMMUNITY**

#### **A. C.C., Prior Resident, Riverside Manor**

Throughout her life, Ms. C. has been a fighter. For 29 years, Ms. C. worked for Hadassah, the Women's Zionist Organization of America, and was a union organizer and leader. When her mental illness made it impossible for her to continue work, she voluntarily entered the Payne Whitney Psychiatric Clinic. After three months, she was discharged with no place to go. The hospital presented Ms. C. with a choice – move to an adult home or a homeless shelter. Ms. C. visited Riverdale Manor, and was affected deeply by what she saw:

“The atmosphere was dreary, the home had not been renovated and was in disrepair.... I went back to the hospital and cried myself into another depressed state.... But I had no choice. I agreed [to go to Riverdale Manor] when my social worker told me it was one of the best and recommended it.”<sup>3</sup>

Ms. C. lived in Riverdale Manor for almost three years. When the State made 60 supported housing beds/units available (to an estimated 4300 adult home residents with mental illness) Ms. C. moved into an apartment of her own. As Ms.

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<sup>3</sup> Unless otherwise noted, all material is from interview of 9/27/10.

C. describes it, she finally had a home to return to. After visiting a friend at Riverdale Manor, she noted:

“[W]hen I came home, I noticed I’d used something that I’ve never used when I lived in Riverdale Manor. I never called Riverdale Manor home. I never did. When I came home, I came in and I sat down and I turned on the TV and made myself a cup of coffee and I realized and I said to myself ‘this is it. This is what I really want and needed.’”<sup>4</sup>

Ms. C. described life in Riverdale Manor bluntly. In the adult home, “you’re not living, you’re existing.”<sup>5</sup> Ms. C. described spending hours daily simply standing in line: four times for medication, three times for meals, and at other times to receive her “Personal Needs Allowance.”<sup>6</sup> Each day blends into the next, in an unbroken routine of tedious repetition. “Living in an adult home is like the same thing happens every day, 365 days a year.”<sup>7</sup>

In the adult home, Ms. C. was denied even the most basic of humanizing factors people take for granted. She had no privacy. At the home “I had to share a

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<sup>4</sup> C.C. video, <http://hub.witness.org/en/upload/choice-housing-cocos-story> (Sept. 17, 2009).

<sup>5</sup> *Id.*

<sup>6</sup> A typical adult home resident receives \$1,368 per month in SSI income. The home receives \$1,190 of that amount, and the remainder (\$178 per month) is paid to the resident as a monthly Personal Needs Allowance or “PNA.” Many adult homes insist that the resident’s entire SSI check be paid directly to the home, and that the home pay the resident the PNA. Some residents are budgeted, meaning that the home doles out the PNA over the course of the month. *See* N.Y. Comp. Codes R. & Regs. Tit. 18, §485.12(a); N.Y. Soc. Serv. Law §130-o (2010).

<sup>7</sup> C.C. video.

room with someone and I had no choice as to whom.... It's close quarters and for you to expect privacy is ridiculous.”<sup>8</sup> Strangers were paired by the adult home without consideration for their individual preference, a situation that often led to stress and tension. When residents requested a change in roommate, Ms. C. reported, the home would generally ignore them.

While the rooms had locks, the housekeepers had keys to all the rooms. This removed the last vestige of privacy. “The housekeepers were generally men. They would just knock on the door and enter, or just enter.” The institutional nature of the adult home was magnified by the control it exerted over the individual's basic lives. Riverdale Manor controlled its residents' medication, distributing it four times a day in a public setting, and their money, requiring benefit checks to be paid to the adult home. It also strictly controlled the items they could possess. With few exceptions,<sup>9</sup> electronic items like irons and coffee makers were forbidden to residents. Ms. C. reported that Riverdale Manor used her PNA as a method to attempt to discipline her, threatening to withhold it if she did not follow instructions.

In Ms. C.'s view, the adult home was not a step towards recovery, but instead saw itself as a place for individuals with mental health issues to spend the

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<sup>8</sup> *Id.*

<sup>9</sup> Residents were allowed items such as a TV, refrigerator, and clock-radio.

rest of their lives. “If I missed an annual function, I would be told, ‘don’t worry, you can go next year.’” When people looked to leave the home, they were asked “why do you want to leave? We take care of you; you have everything here.”<sup>10</sup> No assistance was given to those seeking to move into supported housing, and when one individual got work outside the adult home, she was told to quit the job or move out.

Ms. C. describes her life in her own supported housing apartment as totally different – a life of freedom. (A video of Ms. C. in her apartment is available at <http://hub.witness.org/en/upload/choice-housing-cocos-story> (Sept. 17, 2009).) She relates performing the basic tasks of everyday life – cooking, cleaning, shopping, laundry – with obvious happiness. Ms. C. celebrates the small day-to-day things that people who don’t live in institutions take for granted:

“I’m looking forward to real hot toast. Butter and melt-in-you-mouth warm toast and hot coffee. It’s going to be fantastic.”<sup>11</sup>

Ms. C. says her move to supported housing has improved her physical health. Ms. C. is diabetic, and in the 18 months since moving into supported housing “I’ve lost 20 lbs, and my blood sugar’s under control.” Ms. C. thanks cooking for herself and controlling her own medication for this improvement. By

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<sup>10</sup> *ADA Hearing Before Subcomm. on Constitution, Civil Rights and Civil Liberties 20* (2010) (testimony of C.C.).

<sup>11</sup> C.C. video.

contrast, in the adult home, residents received large portions of carbohydrate-intensive food and the home did not support or encourage residents to choose a healthy diet. Residents were not only denied control over their prescribed medication, but were also refused over-the-counter medication when they requested it.

Ms. C. also reported improved mental health from moving to supported housing. Once in her own apartment, Ms. C. felt safe, secure, and able to recover mentally. She acknowledges that adult homes can play a role in the recovery process, but as a stepping stone to more independent and integrated living.

“Had I stayed, I could not have recovered to the level I have now. I would not have been as healthy, happy and active as I am now.... I needed to move on to recover and to fulfill my life as I have now.”

When asked what it would mean if this Court reversed the trial court’s decision, Ms. C. said that would be:

“one of the worst things that could happen to people now in adult homes. They would be prisoners of adult homes without hope for the future as opposed to being able to move on to other housing and to live normal lives. I feel they deserve better than that.”

**B. I.K., Prior Resident, Surf Manor**

I.K. resided in Surf Manor Adult Home for 16 years before she moved to her own apartment. She described supported housing as:

“Freedom! I’m not wearing a sign pasted to my back saying ‘I’m mentally ill.’ I work on my own [advocacy] projects . . . . An

Empowerment Center is training us as peer advocates, to get Office of Mental Health certification.<sup>12</sup>

On a typical day in supported housing, Ms. K. may shop for necessities, or go to a bookstore or craft shop to support her numerous interests, or for decorations and furnishings for her apartment. She uses her private phone and a cell phone to keep in touch with her friends, many of whom are fellow advocates for people with mental illness. “I do my own cooking, my own laundry, and, when the mood takes me, my own housekeeping. I keep my home neat and wouldn’t be embarrassed to invite you over.”

Ms. K. notes improvements in her mental health and wellbeing after her move to supported housing. When she was discharged from the hospital nearly 20 years ago, she had no option but an adult home. She chose Surf Manor because the staff let residents control their own medication, provided their psychiatrist would authorize it, and let the residents come and go, provided they logged in and out. But, she says, the living situation itself was distressing and debilitating: it was “very disheartening to see so many people in such a hopeless state, sitting in a lobby, watching TV or staring into space.”

She had no choice but to accept the roommate assigned her, and it was difficult to change roommates absent a clear problem. Given the complete lack of

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<sup>12</sup> I.K. is currently training to become a peer advocate so she can help current adult home residents, including those who want to move to supported housing. Unless

choice in roommates and the close quarters within which roommates were forced to live at the adult home, stress and difficulties emerged. For instance, Ms. K.'s first roommate drank alcohol, which presented difficulties for Ms. K., a recovering alcoholic. When she reported this, management told her she did not know what she was talking about. With a later roommate, Ms. K would "sometimes spend nights out of the room . . . wrap myself in blankets and sleep in the lounge or outside on the balcony." With her last roommate, management simply told her to stop complaining, or they would give her a "worse" roommate.

Ms. K. recalls that the staff did not encourage residents to take control over their lives or living conditions:

"It was an atmosphere of intimidation . . . constant threats . . . they would ship residents off to the hospital, evict them without notice. . . . You were treated like children, and everything was done for you. It takes away self confidence . . . *you begin to doubt your ability to start again*, to cope with daily problems, to deal, mentally and emotionally, with paying bills, doing all the things that go with living in your own apartment. You're not encouraged to be an individual. *You're treated at the level of the least functional individual at the home.*"

The home controlled virtually every aspect of Ms. K.'s life. Management assigned seats at meals and decided whether residents could have visitors eat with them. Activities were few, and most were at pre-school level, like coloring books

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otherwise noted, all material is from interview of 9/29/10.

and popsicle stick models. “The most complicated thing they had there was bingo.”

By law, each adult home has a “resident council,” which should give residents a voice to management about conditions in the home. Before Ms. K. was elected president, the council’s meetings were called and run by the home’s administrator. In those meetings, whenever Ms. K. or others requested improvements, such as to food, or in staff attitudes, or to the poorly managed pharmacy, management told them to stop complaining because it was “upsetting other[s].”

The home made little or no attempt to accommodate any person’s medical or religious dietary needs, let alone individual tastes. According to Ms. K., many residents refused to eat the “masses of congealed fat and grease” served at the home. The alternatives of fast-food and junk-food exacerbated many residents’ problems with diabetes and blood pressure. The home’s pharmacy was notoriously slow, with “people waiting for days . . . which led to people being hospitalized unnecessarily.” The lack of adequate adult programs caused Ms. K. and others she knew to smoke more, and it caused their psychiatric conditions to worsen. In Ms. K.’s case, the monotony and helplessness she experienced at the home caused her to slip back into depression, sometimes sleeping the day away for lack of better alternatives.

One of the characteristics of adult homes of which Ms. K. is happiest to be free is the stigmatization she and other residents suffered. “We were pointed out as the crazies – that’s the crazy house. People in the neighborhood shied away from us, they didn’t make contact. I got tired of fighting for my own individuality.”

Now that she has her own apartment, Ms. K.’s friends say she is “a whole different person...not so defensive anymore...more relaxed.” She interacts with her neighbors as she pleases, and the only people who know she has a mental health diagnosis are those she chooses to tell. “It’s a question of how I present myself. I now have control over that.” Ms. K. has quit smoking. “The difference is a lack of stress. When people try to beg for cigarettes from me and I say I don’t have any, I feel great. I feel like a winner.” She eats more healthily, making salads and preparing meals with fresh produce seasoned to her tastes in her own kitchen. “Mine. Nobody else’s. I much prefer doing things for myself.”

Ms. K.’s testimony at trial expresses powerfully what supported housing means to those lucky enough to achieve it:

“It’s free. It’s freedom for me. It’s freedom. It’s being able to actually live like a human being again.”<sup>13</sup>

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<sup>13</sup> JA723.

### **C. P.S., Prior Resident, Bayview Manor**

Mr. S. is a Vietnam War veteran who has a mental illness. When he was released from a V.A. hospital, he was given two options, both adult homes. He chose Bayview Manor. When asked to describe the adult homes, Mr. S. used one word repeatedly: warehousing.

“It’s warehousing. You don’t integrate in the community, because all it is is warehousing.... People sink lower as they live there. Life has to be better than that, just sitting on a park bench, smoking, looking at cars as they pass.”<sup>14</sup>

Mr. S. described an atmosphere of gloom in adult homes. “Wherever you see adult home residents, you see listlessness, hopelessness and despair. You see apathetic people, made that way by the environment.” “People give up – they get medicated and fed and that is all.” Bayview Manor provided no activities other than bingo a couple of times a week. As Mr. S. said, “you can pick out a home by looking at the people outside, [sitting] there, smoking.”

When Mr. S. secured one of the 60 supported housing slots the State made available, Bayview Manor got angry at him for suggesting leaving. Mr. S. reported that the adult home would punish those who rocked the boat. He has heard residents say that the staff threatens them with hospitalization if they complain about conditions or policies at the home.

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<sup>14</sup> Unless otherwise noted, all material is from interview of 9/27/10.

Mr. S. described the contrast between his current life, in his own apartment, and at the institution. At Bayview, “I was treated as a child by people a third my age. There was a disdain for residents that started at the top and went all the way down.” “Residents were treated with complete disrespect. They weren’t treated as adults, but kids. It was more like a detention center than a home.” In his apartment, he lives the normal life of a free adult. He can live without a roommate. At the home, in contrast, he had no choice of roommate, sharing first with an individual who would get up each night at midnight to smoke in the room, and then with an individual with incompatible sleep patterns who woke up at 3 a.m. Now Mr. S. is able to be himself. “I can go out shopping or to see something without worrying about getting home for meals or medication. I have freedom.”

Mr. S.’s life has changed dramatically since his move to supported housing. He has moved from a life controlled by others, woken up at 7:15 a.m. by housekeepers, fed at set times, to one where he gets up when he chooses, makes his own breakfast, is free to read, walk in the park, visit friends, attend Temple, all on his own schedule. He spoke with pleasure of things most people take for granted. He spoke happily of being able to have a phone, and to speak to his family in privacy. (The adult home had no outside phones in the rooms, only expensive pay phones in public areas, and opposed an initiative to provide free cell phones.)

Mr. S. believes adult homes are detrimental to residents' health. Unlike most of Bayview Manor's residents, he insisted on his right to self-medicate, but believes he was permitted to do so only because he went to an outside program each morning, missing the medication call. Mr. S. said Bayview provided no real on-site treatment options for mental health. For physical problems, there was a doctor on site, but Mr. S. insisted on using his own V.A. doctor and social worker. Despite this, Bayside Manor continued to try to control his treatment, even violating his privacy by opening his personal medical mail.

Mr. S. spoke positively of the peace he feels in supported housing, as opposed to the adult home where the close proximity and lack of privacy inevitably led to tension and arguments over minor issues. When asked about the effect of adult homes on healing, Mr. S. was scathing:

“It retards [improvement]. It's warehousing.... Everything is dumbed down to the lowest level, and there's no attempt at social integration for those who would benefit from it.... Life has to be better than this.”

**D. G.L., Prior Resident, Ocean House**

After Mr. L. attempted suicide, he was treated in St. John's Hospital. Upon release the hospital gave him an ultimatum – a choice between a long-term psychiatric facility or Ocean House adult home.<sup>15</sup> Mr. L. described the adult home

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<sup>15</sup> Ocean House was then on the Do Not Refer list because of violations, meaning new residents should not have been referred there.

in stark terms: “the conditions were horrible – it wasn’t right.”<sup>16</sup> However, to avoid placement in a psychiatric facility, Mr. L. chose Ocean House, and lived there for over 5 years until he chose to move to supported housing. The adult home was presented to him as a treatment option, but Mr. L. said he saw no real treatment there.

Mr. L.’s descriptions of life at Ocean House reflect the complete absence of privacy and respect for personal autonomy. His day started at 7:30 each morning, when his roommate’s aide arrived, entering the room without knocking.<sup>17</sup> Although Mr. L and others were provided with keys to their rooms, he later discovered that some keys opened multiple rooms. Breakfast was served at 8 a.m., with residents assigned specific seats at specific tables. This was followed by the residents lining up for medication, which they received and took in public view. Lunch was at 11:30, and dinner was at 4. Dinner was served so early in order to avoid having a separate food service staff – the aides then still working would serve.

Mr. L. described a pervasive atmosphere of disrespect for residents and intimidation of those who didn’t follow administrators’ orders. He was threatened

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<sup>16</sup> Unless otherwise noted, all material is from interview of 9/27/10.

<sup>17</sup> As in other homes, Mr. L. reported that he had no choice in roommate. Fortunately, Mr. L. got along well with his roommate.

with being sent to the hospital if he did not go voluntarily. When there, he found returning to the home depended on him ‘behaving.’

“The head of the unit came to me and told me he wanted to send me home, *but the home administrator wants you to promise if you have complaints, you won’t call the state.* If I had a problem with the home, I was to talk to the administrator. I saw it as a condition of going home, and agreed under pressure.”<sup>18</sup>

Mr. L. witnessed the administrator telling people if they did not attend programs, they would not receive their PNA. He would watch these people get bussed to the program, wander off to sleep, wake up for lunch, sleep all afternoon, return to Ocean House, and only then would the administrator hand them their money.<sup>19</sup> It resembled children being refused their allowance until they obeyed their parents.

The conditions of Ocean House led some to retreat further into a shell, but had the opposite effect on Mr. L.

“Some say living there is the worst thing that every happened to them and their life ended when they did it. It was the opposite for me. It kick started my life. I found a cause because of the horrible conditions and found out I was intended to be an advocate.”

Since this time, Mr. L. has worked tirelessly for the rights of those in adult homes.

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<sup>18</sup> Mr. L. continued to complain directly to the state about objectionable conditions, as was his right.

<sup>19</sup> PNA belongs to the resident, and legally cannot be withheld in this fashion. *See* N. Y. Comp. Codes R. & Regs. Tit 18, §485.12(a)(2).

Mr. L. contrasted his freedom in supported housing with the control the adult home exerts over residents. For instance, Ocean House required Mr. L. to designate the home as the representative payee of his SSI benefits, so that instead of him receiving them directly, they were paid to Ocean House, with the home then paying him his monthly allowance. Often, the home provided this monthly amount late. Mr. L. was not permitted to control his own medication, other than his asthma inhaler. When he sought to move out, he was discouraged from doing so:

“The social workers were very downbeat about it. They told me I could apply, but it would be a long wait, and I might not like the housing I received anyway. In the end all they did was give me phone numbers and tell me I could call to find out what I needed to do to move out.”

Mr. L’s life is now totally different. He controls his own medication, budget, and finances. He handles his own doctor’s appointments and day-to-day living. He cooks for himself and guests. “I can eat what I want when it is convenient – I am not restricted to their times for dinner.” He cherishes this liberty:

“I have more freedom here. And I allow myself the luxury of making multiple choices. When you live in an adult home, it’s difficult to have a group of people come visit you because you live in a place where your room is so small maybe two or three people fit. I actually want to invite people here. When I lived in the home, it was like I didn’t want people coming here. I really didn’t.... This place I want people to come.”<sup>20</sup>

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<sup>20</sup> G.L. video, <http://hub.witness.org/en/upload/choice-housing-garys-story> (Sept. 9, 2009).

Mr. L. believes his health has improved since the move to supported housing. In the home, the doctor associated with the institution ignored his repeated reports of pain, and he was told not to see a doctor attached to an offsite day program. Only after Mr. L. ignored the home's instructions and sought other medical help was he referred to a urologist who diagnosed his kidney stones. In the home, Mr. L. was not permitted to control his medication. One time he saw his dosage of thyroid medication had been changed without any discussion with his doctor, a transcription mistake. But when Mr. L. complained, he was told he was being "paranoid." The institution's rigid medication schedule meant that Mr. L. received his medication at times different than his doctors' instructions. His thyroid medication required an empty stomach, but the home required him to take it immediately after breakfast. Similarly, Mr. L.'s doctor told him to take his sleep aids after 10 p.m., but the home required him to take it at the final medication call at 8 p.m. In the home, the psychiatrist affiliated with the home would see Mr. L. for five minute sessions, not in an office but instead walking through the lobby or on the way from his car. Now that Mr. L. controls his medication and doctor visits and is responsible for his own health, he has seen his medical and physical wellbeing improve.

Mr. L. described how his move to supported housing allows him freedoms others take for granted.

“Ocean House wasn’t the worst place to live, but it wasn’t the best place to live either. The rooms were very small.... You can’t put things on the walls. Why? Because that’s the rules.... You’re not living in a home, you’re living in an institution. Like I have to report my whereabouts, what I’m going to be doing, where I’m going, when I’ll be back.... I feel a lot safer here. It’s a big load off my mind. It’s really good being at my place. It’s going to reflect my emotions, my ego, me.”<sup>21</sup>

## **II. PEOPLE WITH MENTAL ILLNESSES CURRENTLY IN ADULT HOMES BELIEVE MOVING TO SUPPORTED HOUSING WOULD PROVIDE FREEDOM, INTEGRATION INTO THE COMMUNITY, AND IMPROVEMENT IN QUALITY OF LIFE**

The stories below from people who currently live in adult homes show that they would greatly prefer to live in supported housing because they believe supported housing offers the best hope for them to lead successful, healthy lives. All of the adult home residents interviewed believe their physical and mental well-being would improve if they could escape the stigma and restrictions of the adult home institutions and gain freedom and control over their lives.

### **A. Resident I.S.**

Ms. S. is 56 years old and has lived in an adult home since December 2003.<sup>22</sup> Before residing in an adult home, she successfully lived independently. She had two roommates, did her own cooking, cleaning and laundry, and attended college courses.

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<sup>21</sup> *Id.*

<sup>22</sup> Unless otherwise noted, all material is from interview of 10/1/10.

After being hospitalized for a mental health condition, Ms. S. was given no choice but to enter an adult home. Since entering the home, she has “atrophied” and “stagnated.” Life in the adult home is “dehumanizing.” “I go to meals, I go to bed, I watch my soaps, I go to doctors, I don’t live.” Her activities outside the home are limited because the home takes most of her income each month. She comments that being identified as one of several hundred mentally ill persons “warps you and deranges you, to the point where you don’t see the world the same way.” For these reasons, Ms. S. feels relief when she occasionally visits a hospital for asthma and related difficulties: “The hospital is a return to normalcy compared to the adult home. People are normal and they treat me with respect. Life is rooted in reality. The food is decent.” At the hospital, Ms. S. becomes inspired to write poetry again – motivation she cannot muster at the home. “I go back to the home and the sense of normalcy wears away. People are ... angry, they’re paranoid.... I feel lost in the shuffle.”

Ms. S. describes the home as a place run by intimidation. She reports that the operator shouts at residents and pressures them to use medical providers with whom he has some relationship. For example, when Ms. S. first moved to the home, he successfully pressured her to fill her eyeglass prescription at his daughter’s business.

Last year, Ms. S. was forced to throw out most of her personal belongings, including irreplaceable items like original poetry, in response to a widespread bedbug infestation that had gone on for a year before affecting her. The administrator told her the home had retained a lawyer and she would be evicted if she did not follow instructions. The home did not offer to clean or treat her belongings. The home also charged Ms. S. to aircondition her 156 square-foot room (she needs the airconditioning to ease her Chronic Obstructive Pulmonary Disorder and asthma).

For Ms. S., the chance to live in supported housing would be a permanent return to normalcy. “Supported housing is about self-determination. Autonomy is healthy. When I lived independently, I was able to get all of my necessary medical care, socialize with neighbors, attend school – even take care of a dog.” Ms. S. believes that if she could return to supported housing, she would benefit mentally from the stimulation of living out in the world again: “I could go to a consciousness-raising group, or a poetry reading, or see my boyfriend.”

#### **B. Resident S. U.**

Mr. U. and his wife moved into an adult home nearly three years ago. A combat veteran of the Vietnam War, Mr. U. suffers from PTSD. His wife suffers from depression and physical issues. With their only alternative being a homeless shelter, Mr. and Mrs. U. entered the adult home. According to Mr. U., “the adult

home offers a semblance of normalcy” in that it offers three meals a day and a bed, “but all normalcy ends there.”<sup>23</sup> Like many other residents of adult homes, he described it as a “warehouse.” The adult home has a “hotel atmosphere with limited privacy.” The staff “think they can boss you around” and management “generally downplays the number and severity of grievances” raised in resident council meetings.

Mr. U. describes the tedium of life in the home: “There’s nothing to do and nowhere to go.... The staff does nothing to stimulate people to want to participate in the few activities available.” To combat boredom, Mr. U. reads three newspapers daily, does the crossword puzzles and runs errands for fellow residents. His wife has fared much worse. Often she simply stays in her room and “sleeps more, does less.” Mr. U. believes the monotony of the home exacerbates her depression and that the institutional setting does little to facilitate a happy marriage. With unannounced interruptions from staff and nowhere to go in their small room “just for the normal separation married couples need,” their relationship has strained.

Mr. U. believes that moving into supported housing would allow him and Mrs. U to resume a normal, healthy life. Mr. U. would relish the freedoms of coming and going as he pleases, making a cup of coffee when he wants it, and

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<sup>23</sup> Unless otherwise noted, all material is from interview of 9/28/10.

cooking healthy meals for him and his wife. “She likes fish. I don’t love fish, but it’s healthy and she likes it and I’d prepare it well. She likes green vegetables, and so I’d make fresh, green vegetables, not from a can, which is where they come from here.” He is convinced that if his wife had more space and more freedom, her depression would improve. Moreover, the additional space in an apartment would lessen the tension in their marriage. Until then, Mr. U. asks the Court to “walk a month in my shoes. You have to experience [living in an adult home]. You can’t just view it like a movie because it’s not a movie.”

**C. Residents J.S., V.S., C.C., P.B., M.C., S.L., S.V., A.H., J.J., & K.S.**

A group of adult home residents reported the stagnating effect the adult home has had on them. Ms. C.,<sup>24</sup> after 13 years, “feels like I’m losing my skills here. [They] treat us like errant children. Instead of treating us like equals, they belittle us.”<sup>25</sup> And S.L. noted, “[Staff] tell us to go to our room or they’ll send us to the hospital. They have no authority to do that. I’m an adult.” Many residents recounted that staff would threaten hospitalization to coerce residents into complying with staff’s instructions.

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<sup>24</sup> Ms. C. is not the same individual described in Section I.A.

<sup>25</sup> Unless otherwise noted, all material is from interviews of 10/4/10.

Ms. B. said that “[l]iving in the adult home is constant turmoil” and she sometimes feels afraid.<sup>26</sup> The police are sometimes called to the home, as they were recently to remove a youth gang roaming the hallway, vandalizing the building. “There is no peace of mind.”

J.S. and her son V.S live at the adult home. Their third family member, Mr. S., lives in another adult home, over an hour away by public transportation. J.S. and V.S. do not see Mr. S. as often as they would like due to tight finances (most of their income goes to the adult home). J.S. has tried to have Mr. S. move in with them, but their adult home is filled to capacity with 239 residents.<sup>27</sup> When J.S. recently inquired into reuniting her family in an apartment, the home’s assistant administrator told her she was “not ready” and threatened to call the police if she left. Her son does not understand. “Me, mom and dad lived over ten years together before we got separated. We had our good times and bad times but we were all together, and that’s what I miss.... And, I miss my mom’s cooking.”

These residents interviewed agree that moving into supported housing would improve their well-being. They would consider it a privilege to do their own chores, prepare their own meals and keep their own hours. S.V. comments: “I’d

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<sup>26</sup> Some residents have had items stolen. S.V. noted that in response to a bedbug infestation, staff removed all of his personal belongings from his room, including cash and jewelry. “I guess the bedbugs were living in my jewelry,” he quipped.

<sup>27</sup> As J.J. notes, “It’s far too crowded here.”

cook with fresh vegetables and real eggs.<sup>28</sup> I wouldn't put uneaten meals into the soup and serve it the next day." Several of residents would seek paid work or volunteer once they moved into an apartment. "If I could get into supported housing I could get my skills back. I need more purpose in my life. Here, there's no purpose." Residents believe that their mental health would improve if they left the adult home. M.C. noted, "I don't think I would need as many mood stabilizers, because a lot of that is brought on by living here." As J.J. put it:

"I'd have no problem doing my own laundry and cooking and cleaning for myself. That's a normal life. Here, I have no life . . . . it's yelling and screaming, the P.A. blaring at all hours, ordering me to go to too many doctors and not telling me why I'm going. On my own, I'd be more relaxed, and that's healthier."<sup>29</sup>

### **III. THE RECORD IS REplete WITH EVIDENCE THAT SUPPORTED HOUSING IS THE BEST OPTION FOR INTEGRATING AND HEALING PEOPLE WITH MENTAL ILLNESSES**

The personal stories of these *amici* confirm evidence in the record that overwhelmingly shows that qualified persons with mental illnesses prefer supported housing over adult homes and would benefit from it. Like the *amici* here, current and former residents of adult homes, and expert witnesses testified that in these institutions, residents have little privacy, control, or freedom or

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<sup>28</sup> The adult home serves powdered eggs.

<sup>29</sup> S.L. concurs. "I'm a friendly person. I'd meet people, make friends, have them over for dinner."

autonomy over the day-to-day routine.<sup>30</sup> They are confined to rigid institutional routines, and can be threatened with retaliation if they seek improvements or do not conform.<sup>31</sup> They often do not control their medication or finances.<sup>32</sup> They are assigned roommates, forced to eat on a schedule with assigned seating, and isolated from family, friends, and outside interests and employment.<sup>33</sup> Far from being integrated into the community, they are isolated and stigmatized by others.<sup>34</sup>

Such a life can sap confidence and ability or even desire to live independently. Testimony showed that most current adult home residents believe

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<sup>30</sup> *E.g.*, SPA90 (“few or no private spaces in which to receive visitors or talk on the phone; *id.* at 89-90 & nn.58-63( “there are inflexible schedules for meals, taking medication, receiving public benefits, and other daily activities...[r]esidents are assigned roommates and required to sit at a specific seat...in the cafeteria....residents lineup to receive their medications at scheduled times....Long lines also form for receiving personal needs allowances[.]”

<sup>31</sup> *E.g.*, SPA92 n.81; JA161 (threatening to send residents to hospital for not attending day program).

<sup>32</sup> *See* SPA95 nn.108-109 (many residents are not allowed to manage their own medications and are encouraged to let the home administer medication).

<sup>33</sup> *E.g.*, SPA91-92 nn.73-77 & SPA95 nn.105-09; JA60 & SX-151 (E. Jones Report) 4; JA619-20; 634 (residents subject to “quite extensive rules”); JA571 (some adult homes do not allow overnight/opposite sex visitors); JA80-81 (quoting DX-391) (“if [residents] miss medication, they write it up in the charts and they- and then you usually get into some type of trouble); JA391 (many adult homes do not allow residents to manage their own medication).

<sup>34</sup> *E.g.*, SPA99 n.142.

their lives would improve if they moved into supported housing.<sup>35</sup> One adult home resident testified that she believed she “could run an apartment very well” and would like to “live a normal life...[g]etting up in the morning and having daily chores to do. Things to do.”<sup>36</sup> She testified about the adult home, “I think nobody should live like that. As I said, there’s no privacy, no nothing.”<sup>37</sup> Another testified he prefers to do his own chores because “I just felt [] I’m getting the right thing done by doing it myself.”<sup>38</sup>

Trial testimony from the few adult home residents who have moved to independent supported housing also confirms what *amici* say here: that the added privacy, freedom, autonomy, and integration into the community has transformed their lives. They can control their own medication, finances, and schedules, cook healthy meals for themselves, host friends and family for social engagements, and live with their spouses and children.<sup>39</sup> These seemingly small freedoms are

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<sup>35</sup> *E.g.*, SPA153-55 n.552; JA55 (“virtually all of the Adult Home residents [she] spoke with would choose independent living or supported housing if they were given a choice.”).

<sup>36</sup> JA142.

<sup>37</sup> JA141-42.

<sup>38</sup> JA188-89 (S.P.); *see also* SPA 155 (deposition testimony).

<sup>39</sup> SPA112-13; JA163-64; JA165-66; JA170; JA723; PX-546 p. 204:23-205:18.)

themselves vital,<sup>40</sup> and having “normal” lives with the freedom and autonomy that others take for granted invigorates residents in supported housing, improving their health and happiness.<sup>41</sup>

## CONCLUSION

When asked what she wanted to tell this Court as it considers the issues presented here, Ms. C. said:

“Supported Housing allowed me to make a full recovery—it gives you a normal life, lets you do what you want to do, to grow, to go out into society without having a stigma.”<sup>42</sup>

*Amici* respectfully ask this Court to affirm the trial court’s decision. As Mr. S. said, “*There’s a world out there and people...want to join it.*”<sup>43</sup>

October 13, 2010

Respectfully Submitted,

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<sup>40</sup> See SPA113; JA117 (“ordinary and mundane” daily freedoms are “profoundly important to build a sense of well being for the person.”)

<sup>41</sup> SPA113 n.264 (“Compared to Adult Home residents, residents of supported housing have far greater opportunities to interact with people who do not have disabilities and to be integrated into the larger community.”).

<sup>42</sup> C.C. Interview 9/27/10.

<sup>43</sup> P.S. Interview 9/27/10.

## CERTIFICATE OF COMPLIANCE

The undersigned counsel for *Amicus Curiae* certifies

1. This brief complies with the length requirement of Fed. R. App. P. 29 because this brief contains 6,956 words, excluding the parts of the brief exempted by Fed. R. App. P. 32(a)(7)(B)(iii); and
2. This brief complies with the typeface requirements of Fed. R. App. P. 32(a)(5) and the type style requirements of Fed. R. App. P. 32(a)(6) because this brief has been prepared in a proportionally spaced typeface using Microsoft Word 2003 in Times New Roman 14-point font, with serifs.

October 13, 2010

/s/ Elizabeth B. McCallum  
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## CERTIFICATE OF SERVICE

I hereby certify that on October 13, 2010, I caused to be served a copy of the foregoing brief through the Court's Electronic Filing System (CM/ECF) upon the following counsel of record:

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