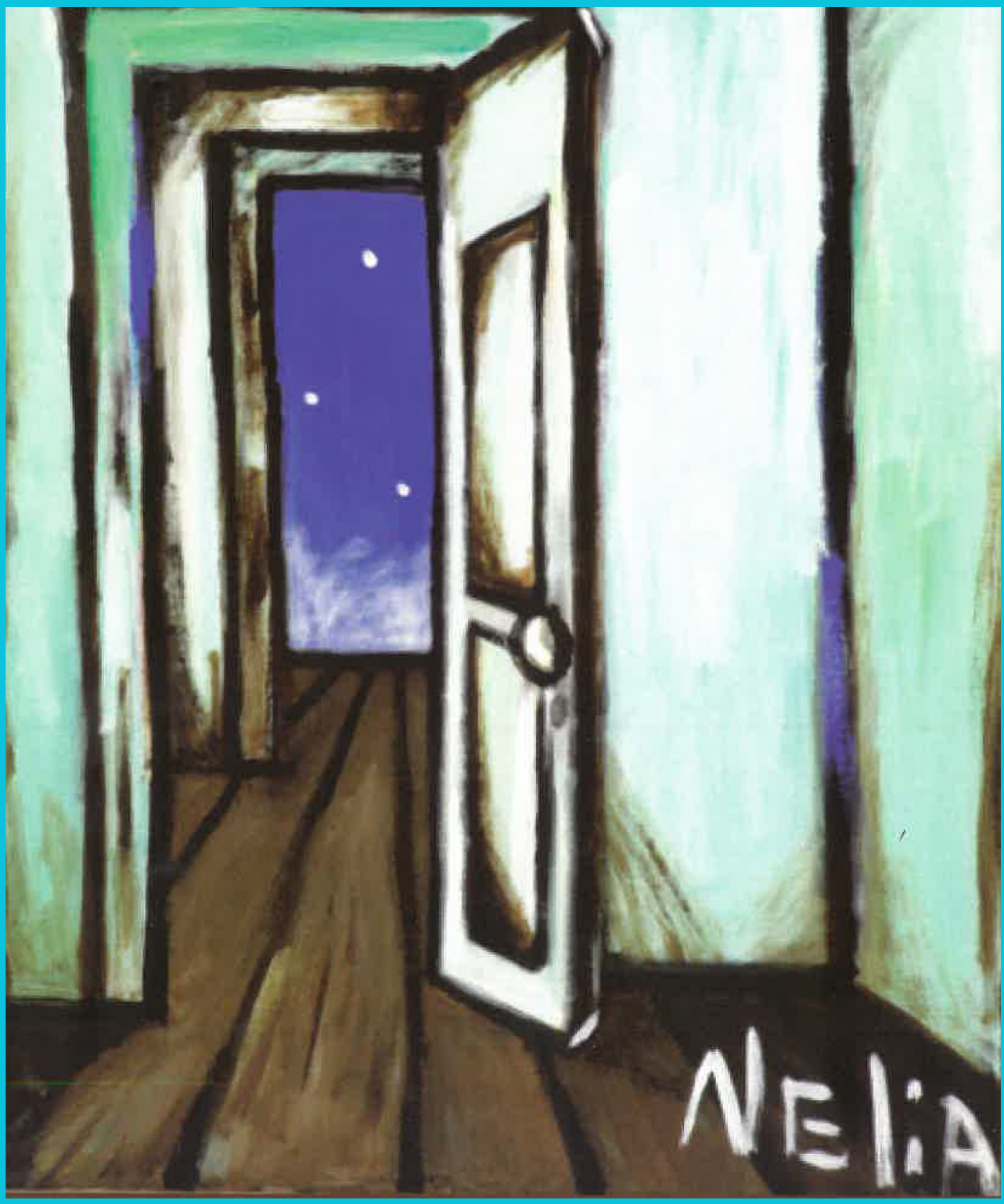
RIGHTS OF ADULT HOME RESIDENTS

A HANDBOOK FOR ADULT HOME RESIDENTS IN NEW YORK CITY



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MOBILIZATION FOR JUSTICE

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MOBILIZATION FOR JUSTICE

Residents' Bill of Rights

1. Your civil and religious rights shall not be infringed. The home must encourage and assist you in the fullest possible exercise of these rights.
2. You have the right to have private, written and verbal communications with anyone of your choice.
3. You have the right to present grievances on your behalf, or on behalf of other residents, to the administration or facility staff, the Department of Health or other government officials or other parties without fear of reprisal.
4. You have the right to join with other residents or individuals to work for improvements in resident care.
5. You have the right to manage your own financial affairs.
6. You have the right to choose your own doctors.
7. You have the right to be informed of your medical condition, proposed medications or other treatment and services, and to refuse medication, treatment, or services.
8. You have the right to privacy in your own room and in caring for personal needs.
9. You have the right to confidential treatment of personal, social, financial and health records.
10. You have the right to receive courteous, fair and respectful care and treatment at all times and you shall not be physically, mentally or emotionally abused or neglected in any manner.
11. You cannot be restrained or locked in a room at any time.
12. You have the right to receive and send mail or any other correspondence unopened and without interception or interference.
13. You can leave and return to the facility and grounds at reasonable hours.
14. You cannot be obliged to perform work. If you work, you must be paid.
15. You cannot provide an operator or agent of the operator any gratuity for services to which you are entitled.
16. If you are involved in an incident or accident, you have the right to have your version of the events included in the report.

You should be given a copy of the bill of rights when you move into a home, and it must be posted in your home where everyone can see it!

Know Your Rights as an Adult Home Resident!

Mobilization for Justice wrote this handbook to educate you about your rights so you will be better prepared to stand up for your rights.

Your rights come from laws and regulations. We talk about these laws and regulations in this handbook. The main laws about adult home residents' rights are found in the New York State Social Services Law (SSL), Chapters 460 and 461. The New York State Department of Health (DOH) enforces these laws and has written regulations explaining in more detail what these rights and responsibilities are. These regulations are in Chapter 18 of the New York Code of Rules and Regulations (NYCRR), Parts 485 through 487. You can get a copy of them on the internet at: www.health.ny.gov/regulations/nycrr/title_18/ or by calling Mobilization for Justice toll free at 877-417-2427.

Some abbreviations you will see in this handbook:

SSL	Social Services Law
DOH	New York State Department of Health
NYCRR	New York Code of Rules and Regulations (DOH regulations)
OMH	New York State Office of Mental Health
CIAD	Coalition of Institutionalized Aged and Disabled
JC	New York State Justice Center for the Protection of People with Special Needs

To ask for more copies of this handbook, to set up a resident rights training at your home, or for legal advice, call MFJ at 877-417-2427

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Moving to an Adult Home

Did you know?

You don't have to move into an adult home if you don't want to. If you choose to move in, you and the home operator will sign an admission agreement, which is a contract between the home and you. If you don't want to move to the adult home, don't sign it. *SSL § 461-c.*

Q&A on Admission Agreements

What is an admission agreement?	An admission agreement is a contract between a resident and the facility, similar to a lease between a tenant and a landlord. The admission agreement describes the resident's responsibilities, including the monthly room and board fee, and the facility's responsibilities, including the services the adult home will provide.
What does it mean when the home signs the admission agreement?	By signing it, the home is making legally binding promises to: • provide room, board and all of the services listed in the agreement and required by law and the regulations; • respect your rights under the law; and • let you stay as long as you want, unless it gets a court order terminating the admission agreement.
What does it mean when I sign an admission agreement?	By signing it, you agree to pay the rent set forth in the agreement and respect the rules. There is a section in the admission agreement where you may also tell the operator if you want the home to hold your money.
Can the home make me stay because I signed an admission agreement?	***No!*** You can leave anytime. See section on Moving Out, page 33.

Living in an Adult Home

MONEY AND OTHER BENEFITS

Benefits can be hard to understand. If you have questions, you can call MFJ or someone else to give you advice. Before you call, ask yourself:

1. What kind of benefits do I get?	Many cash benefits that adult home residents get are listed on the next page.
2. Am I my own payee or do I have a representative payee?	If Social Security thinks you need help handling your own money, it will choose a representative payee to receive your benefits and help you manage your money. The adult home may be your representative payee, but a relative or friend can also be your representative payee. For more information on this issue, see the section on representative payees on the next page
3. Do I have an account with the home?	Adult homes must offer banking services to anyone who gets SSI or Public Assistance and often offer these services to others as well.

NOTE: If you don't know the answers to these questions, you can ask your case manager or call MFJ or an advocate of your choice. You can also request an accounting from the finance department at your adult home to better understand what money you receive.

CASH BENEFITS

This list shows some cash benefits that adult home residents may get. These cover rent at the adult home and sometimes provide spending money, called personal needs allowance. Meals are included in rent, so adult home residents generally can't get food stamps.

SSI/SSP or PA: Supplemental Security Income (SSI) and State Supplement Program (SSP) or Public Assistance (PA)

- **For**: People with no work history or whose benefits from working or retirement are not high enough to pay adult home rent.
- **Benefit Level:** The government sets SSI/SSP and PA rates for adult home residents every year.

SSD: Social Security Disability

- **For:** People who used to work but can't work anymore because of their disabilities.
- **Benefit Level:** Depends on your work history. If your SSD benefits are not enough to pay rent at the adult home and provide you with a personal needs allowance, you should also get SSI and/or SSP.

SSR: Social Security Retirement

- **For:** People who used to work but have reached retirement age.
- **Benefit Level:** Depends on your work history. If your SSR benefits are not enough to pay rent at the adult home and provide you with a personal needs allowance, you should also get SSI and/or SSP.

VA: Veteran's Benefits

- **For:** People who have served in the military and their beneficiaries.
- **Benefit Level:** Depends on service history. If your VA benefits are not enough to pay rent at the adult home and provide you with a personal needs allowance, you should also get SSI and/or SSP.

WHAT HAPPENS IF I HAVE A REPRESENTATIVE PAYEE?

When you have a representative payee, your SSI/SSP, SSD, or SSR payments are sent to someone else, often the home itself. Your representative payee receives your payment and must pay your rent and give you your Personal Needs Allowance. If the home is your representative payee, it might put you on a daily or weekly budget, but it must give you all of your allowance and can't withhold your allowance to control what you do.

How can you find out if you have a representative payee? You can ask your case manager, or you can ask the Social Security Administration by calling them at 800-772-1213 or going to your local Social Security office. You can call the Office of Temporary and Disability Assistance (OTDA) about your SSP benefits by calling 855-488-0541 or emailing otda.sm.ssp@otda.ny.gov.

If you don't want a representative payee, contact your Social Security office and OTDA. If you can show that you can manage your money, the representative payee will be removed. This might require a letter or other form from your doctor. You can also ask for someone else to be your representative payee instead of the home.

Social Security used to mail my checks to me, but they don't anymore. In 2013, the Social Security Administration began changing to a new system where they stopped sending paper checks and started requiring people to have direct deposit. In many cases, residents' SSI, SSD, and SSR payments are now being directly deposited into a bank account that belongs to the home. This is allowed, but you can also use your own bank account if you are your own payee.

If you don't have a representative payee, your payments are sent to you directly. You can decide to have direct deposit into a bank account that belongs to the home, or you can decide to open your own bank account at a bank outside the home. If you need help doing this, you can ask your case manager to help you.

Q&A on Rent

How much do I have to pay?	The amount of your rent is in your admission agreement. The law limits the amount of rent adult homes can charge people who get SSI/SSP and PA. If your income is higher than the SSI rate for adult homes, the home may ask for more but can't charge more than the amount you agreed to in your admission agreement.
Can the home raise my rent?	At the beginning of most years, federal benefits (SSR, SSD, and SSI) increase by a small percentage called a "cost of living adjustment" or "COLA." The state Office of Temporary and Disability Assistance (OTDA) determines how much the PNA and the rent will increase for residents who receive SSI/SSP or PA. If you get SSI/SSP or PA, the home may not raise your rent above the amount set by OTDA. If you get other benefits or have a private source of income, the home may ask for more. You have the right to negotiate a fair rental amount. In either case, the home must give you 30 days' written notice of the proposed rent increase.
When I pay my rent, can I get a receipt?	***Yes.*** You have the right to a rent receipt.

Q&A on Personal Needs Allowance

What is a personal needs allowance (PNA)?	People who get SSI/SSP or PA are entitled to a cash allowance every month to cover personal needs. The amount of PNA is set by the New York State government annually.
Can the home legally withhold my PNA from me?	***No!*** The PNA is yours. Even if Social Security is recovering an overpayment from your check, you are entitled to your full allowance.
What can I use my PNA for?	Whatever personal needs you have or items you want. You can buy newspapers, clothes, books, stamps or a meal in a restaurant. The home may not make you use your personal allowance for things that the home must provide, like soap or toilet paper. Also, you can save your money. But be careful—if you save too much, you can lose SSI, PA and Medicaid. Find out the resource limits for each benefit if you decide to save.
Can the home put me on a budget if I don't want to be budgeted?	Only if the home is your representative payee. If the home is your representative payee, it may help you budget so that your money lasts through the month; however, you still have the right to receive your full allowance over the course of each month. If the home is not your representative payee, it cannot force you to be on a budget.
Can home staff keep my money from me if I refuse to do something they want me to do?	***No!*** Your PNA is yours. Whether the home is your representative payee or you are your own payee, the home may not use your money to control your behavior.
How can I keep my PNA safe?	The home is required to hold your PNA in an account maintained by the home if you choose, or you can open your own bank account.
Do I have to let the home hold my PNA?	***No.*** Unless you have a representative payee and are on a budget, you have the right to receive your full PNA at the beginning of the month and hold onto your own money.

If I choose to maintain an account with the home, when can I get my money out of the account?	The home must provide access to your money at least four hours a day, five days a week. A schedule must be posted in the home and may not be changed without five days' advance notice.
How do I find out how much is in my account?	When you ask for it, and at least every three months, the home must give you a statement of all deposits, withdrawals, and the current balance in your account.
Can I close my account if I want?	***Yes.*** If you are your own payee and decide that you no longer want the home to hold your money, you can withdraw all of it.

OTHER BENEFITS AND SERVICES

Here are some other services and benefits to which you may be entitled:

Access-a-Ride: for people who, because of their disability, cannot use subways and buses. If you apply and are found eligible, you can book door-to-door travel with Access-a-Ride for the price of the bus or subway.

Half-Fare Metro Card: for people with disabilities, including mental health diagnoses. If you qualify, you'll get a picture ID card and can pay half fare on the subway or bus.

Lifeline Telephone Service: If you get SSI or Medicaid, or are low-income, you can get basic landline phone service at a very low monthly cost.

Lifeline Cell Phone Service: If you get SSI or Medicaid, you can get a free cell phone with a limited number of minutes, text messaging, and internet data.

Supportive Housing: Adult homes are only one type of housing for people with disabilities. If you have a mental health diagnosis but want more independent living, ask for help applying for supportive housing.

Telephone numbers for the agencies providing these services can be found on page 34.

Remember: the home is legally required to help you get benefits! If you are having trouble getting the home to help you, contact one of the agencies listed at the end of this booklet

MEDICAL BENEFITS

The list below shows some of the medical benefits that adult home residents may get. They can pay for doctor visits, hospitalizations, rehabilitation, home care, prescription medications, and other services.

Medicaid: for low-income people to pay for all medical care and medications. If you qualify for SSI/SSP or PA, you will automatically receive a Medicaid card. If you don't receive SSI/SSP or PA but are low income, your case manager should help you apply. Medicaid recipients in New York City are now required to enroll in a Medicaid Managed Care plan. Your case manager should help you select a plan.

Medicare Parts A (hospitalizations) and B (outpatient services): for people who have been on SSD for two years or who are over 65, to pay for all medical treatment besides medications. Medicare sometimes has copayments, but they're paid by Medicaid if you have both Medicare and Medicaid.

Medicare Part D: for people who have been on SSD for two years or who are over 65, to cover the cost of prescription medications. If you have a Part D plan and are not on Medicaid, Medicare will cover your prescriptions and you may be asked to pay co-payments for medications. If you have both Medicare and Medicaid, you do not need to pay co-payments for medications.

EPIC: for people over 65 to help cover the cost of prescription medications. If you are over 65 and do not have Medicaid, EPIC can reduce your prescription co-payments.

Managed Long-Term Care (MLTC) Plan: for certain people on Medicaid and Medicare who need long-term care services, like home care. Some adult home residents – but not all – will be required to sign up for a Plan. If you have questions about your eligibility, call New York Medicaid Choice at 800-505-5678. If you are already enrolled in a Plan chosen by the home, you have the right to disenroll and/or choose a different Plan.

Q&A on Medical Benefits

Will Medicaid pay the cost of transportation to medical providers?	***Yes.*** If you are unable to take public transportation, your adult home should assist you to arrange transportation to medical providers and Medicaid will pay for it.
Can I keep my own Medicaid or Medicare card?	***Yes.*** The card is yours. You have the right to keep it, or if it is more convenient, you can ask the home to hold it for you.

Do I have to go to the home's doctors?	***No.*** You are free to choose your own doctors. The doctors provided by the home may be more convenient because they come to the home and accept Medicaid, but the choice is yours. The case manager should help you find another doctor if you need help. To find out what doctors in your area accept Medicaid, call the Medicaid Helpline at 800-541-2831.

Q&A on Pharmacy Co-payments

I can't afford to make my monthly co-payments for medication. Do I have to pay them?	It depends. If you have Medicaid or Medicaid and Medicare, you do not have to pay any co-payment for medication. If you have Medicare only, you can negotiate your co-payments. Figure out what amount you can afford each month and see if the pharmacy will accept that amount. Remember, you can always go to another pharmacy.
Will the pharmacy give me my medication if I don't pay my co-payments?	If you have Medicaid, the pharmacy must give you your medications even if you don't make co-payments. If you are denied a prescription, call the Medicaid Helpline at 800-541-2831. If you only have Medicare and you are not paying the pharmacy at all, the pharmacy can stop providing medications, so it is best if you can work out a plan to pay what you can afford each month.
Can the adult home operator deduct co-payments from my monthly personal needs allowance?	• If you are your own payee, then you control your personal needs allowance. The home should not use your allowance to pay co-payments unless you have authorized it to do so. If you signed an authorization but have changed your mind and don't want the home to make co-payments for you, you can tell the home to stop. • If the home is your representative payee, it can pay your bills for you. But it also has a duty to make sure your day-to-day needs are met. If the home is paying bills from your allowance and you don't have enough left over to pay for the other things you need, tell the home you want it to make smaller payments.

	I have Medicaid or both Medicare and Medicaid	I have Medicare only
I am my own payee	I can tell the pharmacy that I can't afford my co-payments.	I can negotiate my co-payment amounts with the pharmacy. I can try to pay an amount I can afford each month.
The home is my representative payee	The home should tell the pharmacy that I can't pay my co-payments. It should not be using my allowance to pay co-payments.	The home can use my allowance to pay my co-payments. But I should still have money for other day-to- day needs.

Q&A on Resident Councils

What is a Resident Council?	A Resident Council is a group of residents who meet to address problems and concerns of the residents. All residents in the home can participate.
Do all homes have Resident Councils?	All homes are required to have a Resident Council that is run by residents.
What is the relationship between the Resident Council and the administrator?	The Resident Council must be run by the residents – not by staff. The administrator must appoint a staff person to receive complaints from the Resident Council and must make a written reply concerning complaints raised by the Council.
Can adult home staff come to Resident Council meetings?	No, adult home staff cannot come to Resident Council meetings unless they are invited by the Resident Council. Many Resident Councils choose not to invite staff so that all residents feel comfortable discussing their problems. If the Resident Council requests it, the home must provide a representative to attend Resident Council meetings.
How often can a Resident Council meet?	As often as the residents want.
What if I want help organizing a Resident Council in my home?	Call CIAD at 866-503-3332.

Did you know?

Adult homes are required to encourage residents to form Resident Councils.
18 NYCRR § 487.5(b).

Advocacy

An advocate is someone who helps you to stand up for your rights. Adult homes cannot punish, harass or evict you for speaking up for your rights or the rights of other residents.

WHO CAN ADVOCATE FOR AN ADULT HOME RESIDENT?

You: You can stand up for your rights. It is illegal for the home to retaliate against you in any way for asserting your rights.

Resident Council: You can work together with the other residents of your home to make changes and stand up for your rights.

Family, friends, and anyone else who will help you and other residents obtain the rights to which you are entitled by law.

CIAD (Coalition of Institutionalized Aged and Disabled): CIAD works with Resident Councils and Food Committees to make changes in their homes and on policy issues related to adult homes. CIAD can also help people with individual problems at their homes.

Service Providers: Case managers and other service providers can help and support you in standing up for your rights.

MFJ (Mobilization for Justice, Inc.): We can give you legal advice, help you negotiate with the home when you have a disagreement, and represent you in court if the home is breaking the law or trying to evict you. We also represent residents in cases to address patterns of illegal behavior by adult homes.

The Ombudsman Program: The New York City Long Term Care Ombudsman Program works with residents and the family and friends of residents to improve the lives of adult home and nursing home residents

COMPLAINTS AND GRIEVANCES

If your rights are being violated, you can call the state agencies that oversee adult homes and you can call advocates. Adult homes cannot punish, harass or evict you for complaining. Try to keep a record of what happened and when, whom you spoke to at the home about your complaint, how the home responded and the names of anyone who can give more information about the problem. Ask the home for copies of any documents you are given or asked to sign and keep them in a safe place.

WHO CAN I CALL IF I HAVE A COMPLAINT?

DOH: The New York State Department of Health is responsible for enforcing the law and regulations. They investigate complaints and make unannounced inspections of homes. You can complain to DOH by calling their hotline at 866-893-6772 or writing to them. You can also tell DOH inspectors about problems when you see them in your home.

JC: The Justice Center for the Protection of People with Special Needs investigates allegations of abuse and neglect by staff in some adult homes.

Adult Home Services

When you pay rent at an adult home, you're not just paying for a bed. Here are some of the services the home is required to provide under the DOH regulations and your admission agreement:

Furnished Room
The home must provide a single bed, a pillow, a chair, a table, a lamp with a shade, a dresser and closet space, curtains, blinds or shades on the windows and lockable storage.

Linen Service
The home must provide two sheets and one pillowcase, at least one blanket and one bedspread, towels and washcloths. The home must also provide soap and toilet paper as needed. Your linens should be changed weekly or more often if needed.

Housekeeping
The home must maintain a clean and comfortable environment in the home.

Laundry
The home must offer free laundry service.

Food
The home must serve three nutritious meals a day plus an evening snack.

Security
The staff is responsible for supervising the home to protect you and your property.

Personal Care
The home must provide a limited amount of assistance, if you need it, with dressing, bathing, using the toilet, brushing or combing your hair, shaving, caring for your nails, brushing your teeth and eating in the dining room.

Medication Management
If you need help, the home must assist you in taking your medications. If you're able to administer your own medications, the home must offer to help you store them.

Activities
The home must offer an organized and varied program of individual and group activities that help develop your potential as a person. The home should plan an activities program for a minimum of 10 hours per week.

YOUR ROOMMATE AND DECORATING CHOICES.

If you share a room, you must be afforded a choice of roommates. The home must take all reasonable steps to accommodate your expressed choice. You have the right to decorate your room to your taste consistent with fire and safety codes.

Assisted Living Program (ALP) Services

Some adult homes are certified by the Department of Health to offer additional services, beyond what is covered by the room and board rate, to residents enrolled in the home's Assisted Living Program (ALP). These services are paid for by Medicaid.

Personal Care & Home Health Care

The home must provide assistance, if you need it, with dressing, bathing, using the toilet, brushing or combing your hair, shaving, caring for your nails, brushing your teeth and eating in the dining room.

Nursing and Therapy Services

The home must provide nursing services, physical therapy, occupational therapy, and speech therapy to ALP residents, as needed.

Medical Supplies and Equipment

The home must provide some medical supplies, like incontinence supplies, if you need them. The home can help arrange for you to obtain other medical equipment, like hearing aids, through Medicaid, but it does not provide them directly.

Adult Day Health Program

The home must provide an Adult Day Health Program. If you enroll in the home's ALP, you might not be able to attend the same day program you attended before you were in the ALP.

Participation in an ALP is Voluntary

Even if you are eligible, participation in an ALP is voluntary. The adult home should provide you with sufficient information to make an informed decision about whether you want to participate.

Q&A on Case Management Services

I am not sure who my case manager is. How do I find out?	All adult home residents must have a case manager. In smaller homes, the administrator can be the case manager. In larger homes, it must be a different staff member. In some homes, the case manager does not work for the home and instead works for another organization. If you are unsure who your case manager is, you should ask the administrator of your home to tell you.
What is the case manager's job in an adult home?	A case manager should help you adjust to life in the home and to work with you to enhance your independence. A case manager's duties include: • Obtaining copies of important documents, such as your birth certificate, that you might need; • Obtaining replacement copies of documents that you may have lost; • Making sure that you have proper identification; • Helping you find and access services, including banking, education, and job training; • Scheduling medical appointments for you; • Arranging for your transportation to and from appointments related to your medical, mental health, social, and vocational needs; • Helping you access public benefits; • Helping you participate in planning for improvements in the home and to present grievances and recommendations; • Helping you if you want to change roommates; and • Helping you resolve problems that you may have with other residents.
I need help paying the rent in the home. Should my case manager help me with this?	***Yes.*** Your case manager should help you find out if you are eligible for public or private benefits. Your case manager should help you complete applications for benefits within several days of moving into the home or if your benefits are interrupted.

Q&A on Case Management Services Continued

I have a financial problem. Should my case manager help me resolve it?

Yes. Your case manager should help you with financial problems, including when your benefits are denied, delayed, reduced, or interrupted. Your case manager should help you with the following financial problems:

- If you owe rent to the home and you are facing eviction, your case manager should help you apply for assistance before the home takes you to court for non-payment of rent;
- If you have an SSI overpayment and Social Security is taking money out of your check, your case manager should help you apply for a waiver or set up a payment plan;
- If you have an outstanding student loan debt and your benefits are being reduced, your case manager should help you to set up a payment plan and to potentially apply for a discharge of that loan based on your disability;
- If you owe child support or arrears and your benefits are being reduced, your case manager should help you apply for a downward income modification; and
- If you have a dispute or financial problem related to your pensions or other income, your case manager should help you resolve the problem.

Sometimes the government gives one-time or yearly benefits to people. Should my case manager help me get these benefits?

Yes. Your case manager should help you apply for one-time or yearly benefits, including Federal stimulus payments and New York City school tax credits.

I need to see a doctor. Should my case manager help me get an appointment?

Yes. Your case manager should help you schedule appointments with medical providers of your choice and transportation within a reasonable amount of time after you request it.

Q&A on Case Management Services Continued

I need transportation assistance. Should my case manager help me?	***Yes.*** Your case manager should help arrange transportation to appointments related to health, mental health, social, legal, financial, and other services. Additionally, you may be eligible to receive paratransit or discount public transit fares, such as Access-a-Ride and the Half-Fare Metro Card program. Your case manager should help you get these services, including helping you with: • Obtaining applications for these programs; • Collecting and submitting supporting documentation; • Completing the required paperwork and submitting the applications; and • Following-up to make sure that any applications are complete and being processed.
I would like to take public transportation more often, but sometimes I need help. Can my case manager help me?	***Yes.*** The case manager's primary goal should be to work with you to enhance your independence. If you would like assistance learning to ride public transportation independently, ask your case manager.
My case manager does not speak my primary language. Can I still get all of these services?	***Yes.*** You are entitled to case management services in your primary language. If a case manager who speaks your language is not available, your case manager should ask for assistance from other staff members who speak your language, interpreters, or available interpretation services so that you can comfortably communicate with each other.
My case manager has refused to help me with services I need. What can I do?	If your case manager will not provide you with the case management services you need, you should speak with the administrator of your home. If the administrator does not help you resolve the problem, you can call MFJ or any of the organizations or agencies listed at the back of this book.

Q&A on Visitors

Can the home limit when I can have visitors?	***Yes,*** but you have a right to visits during a period of at least ten hours between 9:00 a.m. and 8:00 p.m. daily.
Who can visit me?	Anyone who you want to have as a visitor including relatives, friends, lawyers and other advocates, legal representatives, and case managers. People from community organizations that provide free services or that help you get needed services can also visit.
Can the adult home keep anyone out?	The home can keep out people who would directly endanger the safety of the residents.
What if I don't want to see someone?	You have the right to refuse visitors. If you want to see someone but you or your roommate don't feel comfortable having that person in your room, you can meet elsewhere in the home.
What can I do if I have any problems or questions regarding my right to have visitors?	You can contact any of the organizations listed at the back of this book.

Right to Privacy

The home must allow you privacy in regard to visitors, mail, phones, and personal information. *SSL § 461-d(3).* It must provide space free of charge for you to meet privately with service providers. *18 NYCRR § 487.7.*

Q&A on Mail & Phones

The home opens my mail. Can they do that?	***No!*** It's against the law for the home to open your mail. However, if the home is your representative payee, mail from Social Security will be addressed to the home, not to you, and the home can open that mail.
Do I have a right to access a phone?	The home must provide one telephone for every 40 residents for outgoing calls. If you receive SSI/SSP, PA, or Medicaid, you qualify for a free cell phone (flip phone or smartphone). Call Assurance (888-898-4888) or Safelink Wireless (800-977-3768).
Do I have a right to a phone in my room?	The home does not have to provide one. However, you can pay the phone company for a phone in your room if you choose. If you receive SSI, PA, or Medicaid, you are eligible for a free cell phone (see above) or a discount on landline phone service. Ask the telephone provider about the Lifeline program. Each room must have an emergency call device, like a bell, buzzer or phone.

Q&A on Laundry

What if the home loses my clothes in the laundry?	If you can prove that you didn't get all your clothes back, the home should reimburse you for the cost of replacing them. You might suggest to the administrator that each resident's clothes should be washed in a separate mesh bag. This will help prevent clothes from getting lost. If an item is not returned, report it to the administrator immediately. If your clothes are getting lost in the laundry, you can make a list of what clothing you are sending to the laundry. On the next page is a sample laundry list that you can use. When your laundry is returned, check that all the items are there.
What if I want to wash my clothes myself?	The home might provide machines for your use free of charge. You are also free to go to a laundromat, but you will have to pay.

Sample Laundry List

Date:

Number of:

_____	**Shirts**	*Circle Colors:* black, brown, tan, blue, gray, red, pink, purple, orange, plaid, striped or checked. Other colors: _____
_____	**Pants**	*Circle Colors:* black, brown, tan, blue, gray, red, pink, purple, orange, plaid, striped or checked. Other colors: _____
_____	**Undershirts**	*Circle Colors:* black, brown, tan, blue, gray, red, pink, purple, orange, plaid, striped or checked. Other colors: _____
_____	**Underpants**	*Circle Colors:* black, brown, tan, blue, gray, red, pink, purple, orange, plaid, striped or checked. Other colors: _____
_____	**Pairs of Socks**	*Circle Colors:* black, brown, tan, blue, gray, red, pink, purple, orange, plaid, striped or checked. Other colors: _____
_____	**Nightclothes**	*Circle Colors:* black, brown, tan, blue, gray, red, pink, purple, orange, plaid, striped or checked. Other colors: _____
_____	**Other Items:**	_____

Q&A on Food

Does the law say anything about the quality of adult home food?	The State's rules say that the meals must be "balanced, nutritious and adequate in amount and content to meet daily dietary needs." There must be a hot main course either at lunch or at dinner, and at every meal there must be water, milk, coffee, tea and a hot decaffeinated beverage.
What about special diets, for example, if I have diabetes?	You should let the home know about any special diet before you move in, and you should get a letter from your doctor describing the diet. If the home accepts you for residence, it must provide you with this diet.
Am I entitled to silverware and cups appropriate for the meal?	***Yes.*** The home must provide each resident with silverware, napkins and cups suitable for each meal. The home may not regularly serve food on paper plates or give you plastic utensils to use.
Does the home have to tell residents what it plans to serve at meals?	***Yes.*** Menus must be posted where residents and visitors can see them and include any daily changes or substitutions.
Can meals be served at any time?	***No.*** Meals must be served at regularly scheduled times. The home must serve three meals each day, as well as a nutritious evening snack. The evening meal can be no earlier than 4:30 p.m. Breakfast must be served within 15 hours of the evening meal. For example, if dinner is served at 5:00 p.m., breakfast can be served no later than 8:00 a.m. the next morning.
What can I do if I don't like the food at my home?	You can form or join a Food Committee with other residents of the home. Adult homes are required to allow residents to meet and to advise the operator regarding the food served in the facility. Food Committees can help residents complain to the home and regulatory agencies about the quality of the food, suggest different foods residents would like the home to serve, and work with the home's nutritionist to develop a healthy menu. The home must make a written reply concerning complaints raised by the Food Committee.

Did you know?

A resident Food Committee has the right to meet and evaluate the food service available to residents without interference, and can advise the home about dietary needs, preferences, food quality and safety. *SSL § 461-r.*

Q&A on Security

How should staff keep the home safe?	There must be staff present and on duty at the home 24 hours a day, every day. Staff should make sure that unauthorized people do not come into the home. This means that residents and their guests can come in, but that people who have no business in the home do not. Also, there must be at least one complete fire drill every year.
What about an emergency call system?	Each room must have some emergency call device, like a bell, buzzer or phone, in bedrooms, toilet areas and bathing areas.
What about protecting my property?	Each resident must have lockable storage (a drawer, closet, etc.) in their room. You may wish to keep your valuables locked up in your room, but you should always be careful where you leave cash.
What if I need to store my belongings outside of my room?	The home will usually agree to store a resident's valuables. If the home stores any of your valuables, make sure you make a detailed list of the items you are storing and have a staff member sign the list to show that they received those items for storage. Keep the list in a safe place until you take your items out of storage.
What can I do if something is stolen from my room?	Report any stolen property immediately to the home. You may want to file a police report, too.
What if I think someone at the home is responsible for stealing?	You should tell the home's administration and your Resident Council. If other residents are having the same problem, the home may be able to figure out who is responsible and take care of the problem.
Do I have to give the administrator a key to my room?	***Yes.*** A key is necessary so that the administrator can get into your room in case of an emergency. However, the administrator and staff cannot enter your room without knocking first or without your permission if it is not an emergency.

Q&A on Heat and Air Conditioning

What are the rules on heat in adult homes?	Whenever the outside temperature is below 65 degrees, the temperature in resident bedrooms and in common areas, like the dining room, must be at least 68 degrees.
Is there a different rule for night and day hours?	***No.*** The rules are the same for day and night.
Does the home have to have air conditioning in residents' rooms?	***No,*** the regulations do not require homes to have air conditioning in residents' rooms. However, whenever the temperature in residents' rooms reaches 85 degrees, the home must do the following: • If your room has an air conditioner installed, the home must turn on the air conditioner even if you can't afford to pay for it. • If your room does not have air conditioning, the home must provide a common area where all residents may go in which the temperature is maintained below 85 degrees. Also, whenever the outside temperature reaches 80 degrees, the home must do the following: • take measures to maintain a comfortable environment; • monitor inside temperature, as well as resident exposure and reactions to heat; • provide plenty of water or juice and encourage residents to drink it; • arrange for health care, if needed; and • arrange for temporary relocation of residents, if needed.
I have an air conditioner in my room. Can the home charge me for running it?	***Yes,*** if the home does not receive money from the Department of Health for air conditioning. But the home can only charge you a reasonable fee for running your air conditioner. A reasonable fee is one that is related to the actual cost of buying, storing, servicing, and running air conditioners and using electricity.
What if I think the home is charging me an unreasonable fee to run my air conditioner?	You can complain to the Department of Health or call MFJ.
What if my medication makes me uncomfortable in hot weather?	Ask your doctor about your medication. Some medications make people sensitive to hot weather. Let the administrator know.

Q&A on Medication

What if I don't want the home's help taking my medication. Can I take it myself?	If your doctor states in writing that you are "capable of self-administration" and you keep the home informed of all your medications, you can store and take your own medication.
Suppose I want to take my medication myself, but my doctor disagrees.	You should discuss this carefully with your doctor. If you still cannot agree, you can get an opinion from another doctor.
What if I am found to be capable of self-administering my medication but I want the home to store my medication. Can I do this?	**Yes.** You can ask the home to store your medication. When it is time to take it, ask for it. You should be sure that the label on the bottle is the same as your prescription.
If I am found to be capable of self-administering my medication, how can I get my own medication?	First, your doctor sends a prescription to the pharmacy of your choice. Second, when the pharmacy tells you the prescription is ready for pickup, you go to the pharmacy and purchase the medication with your Medicaid card or other insurance. Third, you take the medication according to the directions on the prescription. Remember, you must let the home know what medication(s) you are taking. Also, you must store your medications in a place where other residents, including roommates, cannot get access to them.
The staff at the home gives me medication. Do I have to take it?	**No.** Under the law, you cannot be forced to take medication. However, the home is required to notify your doctor of your refusal. If there is a danger of harm to you, you may be hospitalized. Also, be careful. Before you decide not to take medication, you should first speak with your doctor and with your case manager.
What if there are unpleasant side effects to my medication? Should I stop taking it?	Before you decide not to take medication, you should discuss the situation with your doctor and case manager and explain the unpleasant side effects. Ask if your medication can be changed to lessen the unpleasant side effects. Some medications need to be reduced over time before they are stopped safely.

Leaving an Adult Home

EVICTIONS: TRUE OR FALSE?

Before you read the following section on evictions, test how much you know about your rights as an adult home resident:

"If the home operator tells me to leave, I have to move." True or False?	***False!*** Only a judge can make you move out.
"If the home gives me a 30-day notice, I have to leave." True or False?	***False!*** If you get a 30-day notice and want to stay, you should tell the operator you object and call MFJ or a lawyer of your choice.
"If the operator takes me to court, I have to leave." True or False?	***False!*** The operator has to prove to a judge that there are legal grounds for eviction and the judge has to order you to leave. If the judge disagrees with the home, you can stay. If you get a notice of petition and petition, it means the home has started a court proceeding and you should call MFJ or a lawyer of your choice.
"If I go to the hospital, the operator can refuse to take me back when I'm better." True or False?	***False!*** That's called an illegal lockout. If your doctors say you're well enough to return home, the home must take you back. Call MFJ or a lawyer of your choice if you want to return to your adult home but are told you can't.
"If I refuse to leave and the home takes me to court, I am more likely to end up in a shelter or in a bad adult home than if I agree to leave when I get a 30-day notice." True or False?	***False!*** Calling a lawyer and going before a judge can help protect your right to get help finding suitable housing. Don't let anyone scare you into moving if you don't want to move.
"If I start using a wheelchair, the operator can make me move out." True or False?	***False!*** That's disability discrimination. Call MFJ or a lawyer of your choice.

TEMPORARY HOSPITALIZATIONS

The only time an adult home can make you leave without a court order is if you need medical hospitalization or if you become a danger to yourself or to others and need psychiatric hospitalization. In both cases, you have the right to return to the home once your doctors decide you are ready.

Under Social Services Law Sections 461-g and 461-h, an adult home operator cannot make you leave without a court order. If the home is trying to make you leave, call MFJ or a lawyer of your choice.

Q&A on Evictions

Can I be evicted from the home?	***Yes.*** You can be evicted if: • you do not pay your monthly rent, • you become so sick that you can't get necessary care in the home, • your behavior is dangerous to yourself or others, • your behavior is repeatedly disruptive, or • the home is being closed. But, you cannot be evicted because: • you make a complaint about the home, • your income is reduced due to an overpayment, • you stand up for your rights, • you use a wheelchair • you contact a lawyer, or • you are temporarily hospitalized.
What happens if I sign an agreement to leave voluntarily?	Call MFJ or an attorney of your choice if you signed something agreeing to leave the adult home but you don't want to leave. You may be able to withdraw the agreement and stay.
What if I owe the home money, but I don't have it? Won't the judge put me out?	Not necessarily. It may be possible to get public assistance or charity funds to prevent eviction. The judge will usually give you time to get this money. In fact, the home has to help you get the money.

The Eviction Process

(SSL 461-g and 461-h)

The home gives you a 30-day notice. The notice must state why the home wants you to leave and when.

If you don't want to leave, tell the home you plan to stay. If you want to leave, tell the home you want help finding another place to live, but plan to stay at the home until you find another place. Either way, call MFJ.

After 30 days, if the home wants to evict you, it must serve you with eviction papers called a Notice of Petition and Petition. If you received such papers and haven't called MFJ already, call now!

The home must prove to the judge that there is a legal reason you should be evicted. If the home cannot prove this, you don't have to leave. Even if the judge agrees to evict you, they will probably give you some time to work with the home to find another place to live.

Q&A on Involuntary Hospitalizations

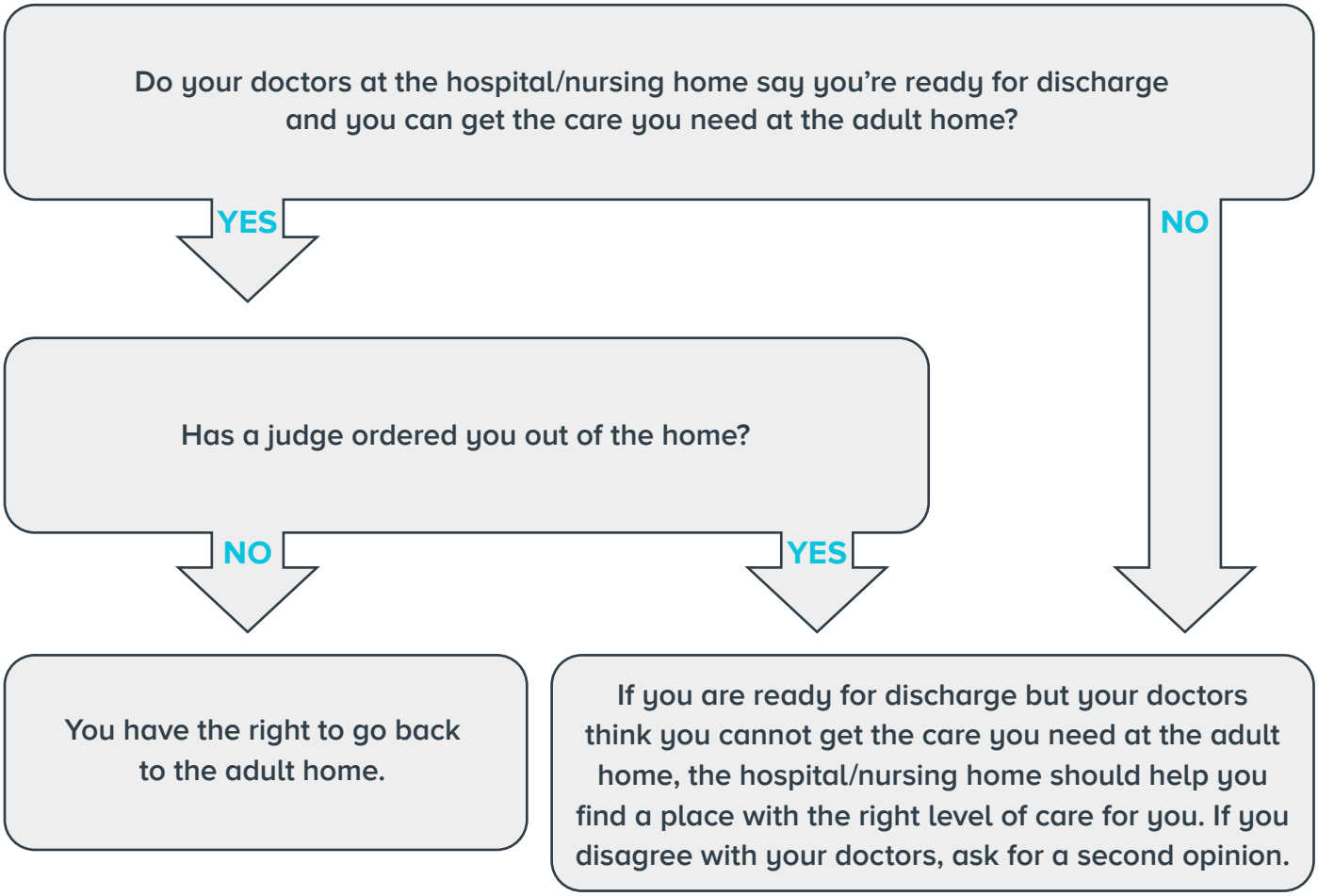
What should I do if the home wants to send me to a psychiatric hospital and I don't want to go?	The most important thing that you can do is to stay calm: take a deep breath, count to ten or suggest to staff that you go to your room so that you can calm down. Even if staff is doing something you know is wrong, it's in your best interest to remain calm. You should also try to remain calm if the home calls the police or an ambulance to take you to the hospital.
What are my rights if I'm admitted to a psychiatric hospital against my will?	You can get a lawyer from the Mental Hygiene Legal Service (MHLS) to challenge your hospitalization. MHLS has an office in most psychiatric hospitals and the number for the MHLS attorney for that hospital should be posted in the psychiatric unit. You can also tell a social worker on the unit that you want to speak to an MHLS attorney. If you want to be released, MHLS can help you to get a hearing.
If I signed myself into the hospital voluntarily, can I change my mind and get out of the hospital immediately?	***No,*** you must notify the hospital staff in writing. The hospital must either release you or apply for a court order to keep you within 72 hours. You again have the right to get help from an MHLS lawyer.
Will I continue to receive SSI while I am in the hospital?	Your SSI can continue for three months while you are hospitalized if Social Security is notified that your stay is likely to be less than three months. Remember, SSI pays to hold your bed at the adult home while you're away. If you are in the hospital for more than 3 months, you may lose your bed, but you still have the right to return to the next available bed.
When I'm ready for discharge, can the home "screen" me or make me do another admission interview?	***No.*** As long as your doctors at the hospital state that an adult home is appropriate for you, you have the right to return. If the home refuses to take you back or insists on screening you, you can call MFJ or a lawyer of your choice.

Did you know?

It is illegal for adult homes to use hospitalizations or the threat of hospitalizations as a way to punish people for standing up for their rights and making complaints. *SSL § 461-d(3)(c).*

When You're Sent to a Hospital or Nursing Home

Sometimes you may need to leave the home for short-term medical or mental health treatment. When you're ready for discharge, you have the right to go back home. If the hospital sends you to a nursing home for rehabilitation, you can go back to the adult home when you finish rehabilitation and the doctors think you're ready to return to the adult home. Use this flow chart to figure out your rights after you've been admitted to a hospital or nursing home.



Social Services Law 461-g and 461-h say that only a judge can order you out of a home. The home can't use hospitalizations as a way to terminate your admission agreement. If you are *not* ready for discharge from the hospital or nursing home, the adult home must hold a bed for you until you are ready to go home. When your doctors say you're ready to go home, the home can't refuse to take you back.

Q&A on Moving Out

Can I move out of my adult home if I want to?	***Yes.*** You are free to leave at any time.
How can I find another place to live?	If you are interested in moving out, you can ask your case manager for help. Your case manager should help you complete housing applications. Your case manager should help you by: • Helping you complete housing applications; • Gathering required documentation; • Monitoring the progress of the application after it is submitted; and • Providing follow-up as needed.
The adult home case manager won't help me look for another place to live. What should I do?	You can complain to DOH.
Who else can help me find another place to live?	In New York City, you can call 311 and ask for assistance with applying for affordable housing through NYC Housing Connect.
When do I stop paying rent if I move out?	You should give your home advance notice of your decision to leave so you can stop owing rent the day you move out. Most admission agreements state that the resident should give 30 days' advance notice. If you move before the end of the month, and gave 30 days' notice, your rent for the last calendar month will be pro-rated on a daily basis, so you will only owe rent for the days you lived at the adult home.

Benefits for Adult Home Residents

You can call the following numbers for helpful information about benefits and services that may be available to you. Remember that if you are calling with specific questions about your benefits, it helps to have information about yourself ready, like your Social Security number or benefits ID number.

Access-a-Ride
Call Access-a-Ride at 877-337-2017.

Lifeline
Call your phone company for landline phone service.
Call Assurance Wireless at 888-898-4888 or Safelink Wireless at 800-977-3768 for cell phone service.

Medicaid
Call the Medicaid Helpline at 800-541-2831.

Medicare
Call Medicare at 800-MEDICARE; 800-633-4227.

MTA Half-Fare Card
Call the MTA at 511, say "MTA," then say, "Subway and Buses," and follow the prompts.

SSI, SSD and Social Security Retirement benefits
Call the Social Security Administration at 800-772-1213.

SSP State Supplement Benefits
Call OTDA's State Supplement Program at 855-488-0541 or email otda.sm.ssp@otda.ny.gov.

Supportive Housing or Case Management
Call the Center for Urban Community Services (CUCS) at 212-801-3300.

Veterans' Benefits
Call the Veterans' Administration at 800-827-1000.

Organizations that Help Residents

The Adult Home Advocacy Project of Mobilization for Justice, Inc., provides free legal services to adult home residents. MFJ used to be named MFY Legal Services. MFJ is located at 100 William Street, 6th Floor, New York, NY 10038. Contact MFJ by calling **877-417-2427.**

The Coalition of Institutionalized Aged and Disabled (CIAD) helps residents of adult homes to organize Resident Councils and Food Committees and helps existing Councils and individuals to address problems related to resident care. CIAD also provides training sessions for residents who seek to become more independent and gain greater control over their lives. Contact CIAD at 205 Hudson Street, Suite 746, New York, NY 10013 or by calling **866-503-3332.**

The New York City Long Term Care Ombudsman Program works with residents, and the family and friends of residents, to improve the lives of adult home and nursing home residents. You can reach the program c/o the Center for Independence of the Disabled, 841 Broadway, Suite 301, New York, NY or by calling:
212-812-2901 (Manhattan, Bronx, Staten Island) or
212-812-2911 (Brooklyn & Queens).

The New York State Department of Health (DOH), Division of Adult Care Facility/ Assisted Living Surveillance is the government agency that licenses and regulates adult homes. You can file a complaint by calling **866-893-6772**, writing to the DOH Adult Home Complaint Intake Unit, 875 Central Avenue, Albany, NY 12206 or by faxing your complaint to **518-408-1249**.

The Justice Center for the Protection of People with Special Needs (JC) is the government agency that investigates abuse, neglect, and mistreatment in adult care facilities: 1) that have over 80 beds; 2) where at least 25 percent of the residents have serious mental illness; AND 3) where less than 55 percent of beds are Assisted Living Program (ALP) beds. If you suspect abuse, neglect, or mistreatment by staff at an adult care facility that meets these three requirements, you can report it to the Justice Center by calling **855-373-2122.**

The New York State Office of Mental Health (OMH) is the government agency which licenses and regulates mental health providers, including hospitals, outpatient clinics and OMH case managers. You can file a complaint by writing to 44 Holland Avenue, Albany, NY 12229 or calling **800-597-8481.**

Cover Art
Nelia Gibbs, *Green House.*

About the Artist
Ms. Gibbs was born in 1961. She began exhibiting her artwork in high school, studied at the Art Students' League, the School of Visual Arts, and the Jamaica (New York) Art Center. Ms. Gibbs has lived with paranoid schizophrenia for many years. She says that she accepts her illness and the need to take medication for it as part of her reality. She joined Fountain House, a club house for people with mental illness, because of its gallery. She has exhibited her paintings in group shows and in a two-person show at Fountain Gallery and through Club Access, a non-profit group working with artists. She hopes that her work will provide hope and inspiration to adult home residents who are seeking to express themselves by advocating for their rights.

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