If you participate in a community integrated living arrangement (CILA), community living facility or other community-based program for people with intellectual or developmental disabilities, you have many rights. You have the right to be as independent as possible and to be involved in the decisions that affect your life.

This fact sheet discusses many of your rights in community-based programs and the circumstances under which a program may restrict your rights.
Right to Adequate Care and a Customized Service Plan
While living in a CILA or other community based home, or while participating in any daytime program, you have the right to have your needs met and have your wishes respected. The program should give you as much freedom as possible and restrict that freedom only when it is not safe for you or others in the program.

The program must develop a plan for you that supports you, allows you to do the things that are important to you, and meets your needs. The plan must be regularly reviewed. You have the right to participate in developing that plan, and you also have a right to choose someone, such as a family member or trusted friend, to participate in the process with you. If you have a guardian or another person who has the legal authority to make decisions for you, that person also has a right to participate in preparing and reviewing your plan.

Right to private and uncensored communication
You have the right to send and receive mail, to make and receive phone calls, and to have visitors. Program staff may not read your mail, listen to your phone calls, or sit in on visits. Your program may set reasonable times and places for calls or visits. Program staff may restrict your communication only when it is necessary to protect you or others from harm, harassment or intimidation.

Right to keep personal property
You have the right to have and receive your own personal property while participating in your program. Program staff may take your personal property only if it is illegal to have those items, or if it is necessary to protect you or others from harm. Any lawful personal items the program staff takes from you must be returned to you when you are no longer participating in the program.

Right to be free from abuse, neglect and financial exploitation
No one has the right to ignore your needs, take advantage of you, misuse your money, or hurt you physically, sexually or emotionally. If you believe someone is hurting you, failing to take care of your needs, or taking or misusing your property or money, you should report your concerns to: Department of Human Services, Office of the Inspector General Hotline at 1-800-368-1463.

For more information, please see the EFE fact sheet on Responding to Caregiver Abuse, Neglect and Exploitation.
Right to have and use money
You are allowed to have money and use it any way you want unless you have a guardian who makes those decisions for you. You may deposit your money with the program or a financial institution, such as a bank, during your participation in the community program. Your program must return your money, with any interest it earned, when you leave the program. You should request and receive a signed receipt if you deposit the money with your community program.

Although you have a right to keep money, you should be careful not to share details about your money, such as how much money you have and where you keep it, with others in the program whom you do not trust.

Rights regarding medical care
You have the right to participate in your healthcare decisions and medical treatment as much as you are able to. Your program should evaluate you to determine if you are able to take medication on your own. Program staff should take steps to help you take your own medication, such as opening the locked cabinet where the medication is stored or opening the medication container for you if you need assistance. If you are not able to administer your own medication, your program should provide you with training on how to safely take medication yourself.

You have the right to choose your own doctors and other medical providers. Before you receive any medication, your medical provider should inform you of the reason for the medication and any risks of taking the medication. Your medical provider should make sure you understand the information before asking you to consent, or agree, to taking the medication. A medical professional should be available at all times to answer your questions or help you with any of your medical needs. You may request review of your program and clinical records at any time.

You have a right to refuse medical and dental care during your participation in the community program. If you have refused medical or dental care, your program cannot provide you with the care unless it is an emergency and your doctor has determined that you are not able to adequately understand information regarding the medical or dental care.

Right to refuse services
You have a right to refuse any and all services offered to you during your participation in the community program. If you refuse services, your program may not provide the services unless they are necessary in an emergency to prevent you from causing serious and immediate physical harm to yourself or others. In limited situations, a judge may also enter a court order allowing the administration of psychotropic medication against your wishes. Psychotropic medication can affect your behavior, emotions and mental ability. Examples include mood stabilizers, antipsychotics and antidepressants. Many requirements must be met before a court can enter an order, and you have many rights in connection with the court hearing. For more information, please see the EFE fact sheet on Involuntary Treatment in Mental Health Facilities.
If you refuse medication or other services, your guardian cannot consent against your wishes unless he or she receives a court order. If another person is authorized to make decisions for you, he or she cannot provide consent against your wishes unless he or she receives a court order, or you previously gave that person the right to do so in a legal document called an Advance Directive.

When you begin your participation, or anytime thereafter, you may tell staff in your program the names of any people or organizations you want notified if the provider has given you services against your wishes or has otherwise restricted any of your rights. The provider must notify those people or organizations anytime it violates one of your rights.

Right to end your participation

If you no longer wish to participate in your community service program, your provider must allow you to leave the program. If you want to stay in your program, you have a right to stay unless the program determines you are no longer appropriate for services.

Your participation in the program can be reduced or terminated for only a limited number of reasons. You should have an opportunity to ask for review of the decision to reduce or terminate services. For more information on your rights regarding reduction or termination of services, please contact one of the organizations at the end of this fact sheet. Please note that there may be short time frames for asking for review of the program provider’s decision.

For more information:

Equip for Equality: 1-800-537-2632 or 1-800-610-2779 (TTY)
Illinois Guardianship and Advocacy Commission: 1-866-274-8023 or 1-866-333-3362 (TTY)
Individual Service and Support Advocacy (ISSA) agency. To find the contact information for your ISSA agency, call 1-866-337-5267.
Department of Human Services, Office of the Inspector General: 1-800-368-1463 (Voice/TTY)
Department of Human Services, Division of Developmental Disabilities: 1-888-337-5267

This resource material is intended as a guide. Nothing written here shall be understood to be legal advice. For specific legal advice, an attorney should be consulted.