Rights of Individuals in Medicaid Home and Community-Based Services Developmental Disability Waivers

Accessible Version

June 2017
This accessible version of Rights of Individuals in Medicaid Home and Community-Based Developmental Disability Waivers was developed with input from self-advocates in Illinois and support from The Alliance, a statewide team of self-advocacy groups working together to make life better in their communities and services better in Illinois.

The Accessible Version is meant to support greater understanding and advocacy of the rights of individuals receiving services in the Medicaid Home and Community-Based Developmental Disability Waivers programs. The rights statements can be found at www.dhs.state.il.us/onenetlibrary/12/documents/Forms/IL462-1201.pdf

**Retention of Rights**

**What It Says**
You maintain all of your legal and civil rights while receiving services.

**What It Means**
You have rights. The agency who gives you services cannot take away your rights.

![Person with arms stretched out holding scale in each hand, scales are equal](image-url)

- Original wording of right
- Name of the Right
- Easier-to-understand wording of what the right means
- Picture that helps visually explain what the right means
- Words that describe picture

The Alliance is proud to be an initiative of the Illinois Council on Developmental Disabilities

www.illinois.gov/icdd

www.selfadvocacyalliance.org
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![Balance Scales](person with arms stretched out holding scale in each hand, scales are equal)

Non-Discrimination

**What It Says**
You have a right to be treated fairly without regard to your sex, race, religion, ethnic background, handicapping condition, national origin, age or financial standing.

**What It Means**
I have a right to be treated like everyone else. I have a right to be treated fairly no matter what. It doesn’t matter
- how old I am
- how much money I have
- if I am a man or a woman
- the color of my skin
- where I am from
- what my religion is
- what kind of disability I have

![Different Sizes and Shapes](different sizes and shapes of people holding hands)
Selection of Providers

What Is Says
You have the right to choose your own providers and change providers if necessary. You should contact your Independent Service Coordination agency (ISC) for assistance with this. You have the right to know if the service provider is not meeting quality standards and to look at written review and survey reports describing the quality of the services. Review and survey results are posted on the Department's website for your information. Summary data about allegations of abuse, neglect, and exploitation is posted there as well. Information about allegations at specific sites is available upon request from your ISC agency.

What It Means
I have the right to choose the agency where I want to get services. I can switch agencies if I want, and my Independent Service Coordinator will help me. I have a right to know if my agency does a good job providing services. I can look at survey reports to learn more about the agency; if I need help to find the information, my Independent Service Coordinator will help me.
Humane Care and Services Plan

What It Says
You have a right to adequate and humane care, services in the least restrictive environment and an individual service plan. You have the right to participate in the development of your own individualized service plan.

What It Means
I have a right to get good care from people who respect me, listen to me, support me, and treat me well.

I have the right to have a Person Centered Plan (or PCP) that’s all about me and I can help plan it. Person Centered Plans (or PCPs) have many names

- Individual Service Plan or ISP
- Individual Habilitation Plan or IHP
- Individual Program Plan or IPP
- My Goals and Objectives

I have the right to ask people to attend my planning meeting, including my family members and advocates. I don’t have to invite my family if I don’t want them at my meeting.
Abuse or Neglect

What It Says
You have the right to be free from physical, sexual and mental abuse or neglect. If you think someone has treated you badly, or has taken advantage of you, you should tell someone you trust so that the problem can be resolved. Any incidents of abuse or neglect shall be reported to the appropriate agency listed on page 3 for "Filing A Complaint."

What It Means
I have a right to be safe and feel safe. It is wrong for anybody to hurt my body or my mind. Some things that hurt my body or mind are

Physical Abuse
- hitting or punching
- kicking
- pushing/shoving
- strangling/choking

Sexual Abuse
- looking at or touching my private parts without permission
- making me touch someone else’s private parts
- making me have sex without my permission

Mental Abuse
- calling me names or cursing at me
- bullying me

Neglect
- not giving me medications
- not giving me food
- not meeting my physical needs

I have a right to tell my safe person or a person I can trust if my body or your mind has been hurt; if I tell someone who works at the agency, a person will investigate it and help me to be safe. It might take a long time for me to feel safe again.
Exploitation

What It Says
You have the right to be free from exploitation of your property or finances. If you think someone has taken advantage of you, you should tell someone you trust so that the problem can be resolved. Any incidents of exploitation shall be reported to the appropriate agency listed on page 3 for "Filing A Complaint."

What It Means
I have a right to have my money and personal belongings. It is wrong for someone to take my money or personal belongings. I have a right to tell someone if my money or personal belongings have been taken; if I tell someone who works at the agency, a person will investigate it.

Coercion

What It Says
You have the right to be free from coercion. You have the right to be free from others pressuring you to do something using force or threat.

What It Means
I have a right to not have people tricking me to doing things that I don’t want to do. I also have the right to be safe from people forcing me to do things I don’t want to do or people saying they will hurt me or take things away from me if I don’t do what they want me to do.
**Restraints**

**What It Says**
Restraints may be used only to protect you from physically harming yourself or others, or as a part of a medical/surgical procedure, and only under the supervision of a properly qualified professional.

**What It Means**
Nobody should hold my arms, legs or body down unless it is to keep me from hurting myself or someone else or as part of a medical procedure. Only a person trained to help me be safe can help me not hurt myself or someone else.

- hand grabbing arm
- person wearing jacket that ties arms to the body being walked by people on either side

**Seclusion**

**What It Says**
The use of seclusion is not permitted.

**What It Means**
It is wrong for staff or anyone to punish me by keeping me away from other people or making me stay in a room by myself. I have a right to be alone in a room if I want and if I choose to.

- man sitting in the dark and crying
- woman sitting in the dark and crying
- locked door
Confidentiality

What It Says
Personal information about you and the services you receive is private and may be shared with someone else only if allowed by the Illinois Mental Health and Developmental Disabilities Confidentiality Act, and, if applicable, by the federal Health Insurance Portability and Accountability Act.

What It Means
I have a right to have all information about me kept private. Agency staff can’t talk about me or my services in front of anyone but me or my legal guardian if I have one. If someone needs information about me, I must sign a paper giving permission to see my record or get information; if I have a legal guardian, my guardian will sign the permission paper. I have a right to change my mind and the permission paper to stop giving my information out; if I have a legal guardian, my legal guardian can change the permission paper.

- person with finger over lips as if saying “shhhhh”
- person with closed zipper for lips
- folder with word Confidential written on it in red
Mail/Phone Calls/Visits

What It Says
You have the right to communicate with other people in private, without obstruction or censorship by the staff. Communication by these means may be reasonably restricted, but only to protect you or others from harm, harassment, or intimidation.

What It Means
I can get mail and have phone calls and visits in private. People who visit, call or send mail to me might include

- Family and friends
- Co-workers
- Church members
- Boyfriends/girlfriends
- Service providers

Staff may need to help me or others be safe with mail, phone calls, and visits; if I have a legal guardian, my guardian will help me make that decision. That decision will be written into my plan.

![mailbox with envelopes](image1)

![telephone](image2)

![two people ringing a doorbell at a front door](image3)

![two people sitting at a table and talking](image4)
Property

What It Says
You have the right to receive, possess, and use personal property unless it is determined that certain items are harmful to you or others. When you stop receiving services from an agency, all lawful property must be returned to you.

What It Means
My personal things belong to me. These things include my clothing, electronics, cell phones. My things can only be taken away if they are hurting me or someone else; if that happens, it will be written in my file. If I leave the agency, I can take all personal things with me.

clothing

[Image of clothing]

television

[Image of television]

cell phone

[Image of cell phone]

stereo

[Image of stereo]
Money

What It Says
You may use your money as you choose, unless you are prohibited from doing so under a court guardianship order.

What It Means
I get to decide what I do with my money. I can ask staff to help me keep my money safe or help me save my money. I can ask staff to help me buy things with my money. If I have a legal guardian, my legal guardian may not let me do what I want with my money, and that will be written in my file.

paper dollar bills and coins
Banking

What It Says
You may deposit your money at a bank or place it for safe-keeping with the service provider. If the service provider deposits your money, any interest earned will be yours. Neither this service provider nor any of its employees may act as payee to receive any assistance directed to you, including Social Security and pension, annuity, or trust fund payments without the informed consent of you or your guardian.

What It Means
I get to decide what I do with my money:
- I can ask staff to help me keep my money safe
- I can ask staff to help me save my money
- I can ask staff to help me buy things with my money

If I get help with my money, I will get a report every three months that will show me how my money was spent. If I have a legal guardian, my guardian will get the report every three months.

If I have a legal guardian, my legal guardian may not let me do what I want with my money, and that will be written in my file.
Labor

What Is Says
You must be paid for work you are asked to perform which benefits the service provider; however, you may be required to do personal housekeeping chores without being paid.

What It Means
I will get a paycheck if I do work for the agency. The work might be janitorial, piece work, or working with food. I won’t get paid if I have to clean up my room, do my laundry, or cook my own food.

- bucket and cleaning supplies
- washing machine and basket of clothing
- cookbook and cooking supplies
- person working on piece work
Refusing Services

What It Says
You or your guardian (on your behalf) have the right to refuse services, including medication. In general, when services are refused, they will not be given to you. However, they may be provided even if you refuse if there is a medical or other emergency or if a judge orders it.

What It Means
I have a right to know about medications and services in a way that I can understand. I can say no to services and medications; if I have a guardian, my guardian will help me make those decisions. My decisions will be written in my file.

angry face putting up hand to stop something

person putting up hands to stop something
Medical or Dental Services

What It Says
Except in an emergency, no medical or dental services will be provided to you without the informed consent of you or your guardian. You have the right to purchase and use the services of private physicians and other professionals of your choice. Your choice shall be documented in your service plan.

What It Means
I get to choose my doctor(s) and my dentist. If I have a legal guardian, my legal guardian will help me choose my doctor(s) and dentist, and that will be written in my file. If I have an emergency, staff or someone will call 911 and I won’t get to choose who helps me. An emergency might be
• Heart attack
• Really low blood sugar
• A big seizure
• Really bad injury ~ broken bones or lots of blood
Meetings

**What It Says**
You have a right to participate in any team meeting about you.

**What It Means**
I am important. I can go to any meeting that is about me ~ nothing about me without me! I have a right to understand what is being said; a right to ask questions; and a right to make my own decisions.

![people sitting around a table putting a jigsaw puzzle together](image1)

Discharge

**What It Says**
You have a right to continue to receive services unless you voluntarily withdraw or you meet the criteria for discharge from the services. You have the right to terminate services at any time.

**What It Means**
I choose where I want to be. I can keep getting services until I say I don’t want them or if the agency says I don’t need them anymore; if I have a guardian, my guardian will help me make that decision. I can stop getting services any time I want.

![person opening a door for another person to walk through](image2)  ![person moving a stack of boxes](image3)
Grievances

What It Says
You have a right to express grievances in writing to the chief of the agency providing your services. Some decisions by the agency (denial, reduction, suspension, termination of services) are appealable to the Department of Human Services and to the Department of Healthcare and Family Services.

What It Means
If I don’t like what is happening at the agency, I have a right to let people know. I can write a letter to the person in charge. I can let the Department of Human Services and the Department of Healthcare and Family Services know if I don’t like some of the decisions the agency has made, such as

- Not giving me services
- Changing my services so I have less
- Making me leave services for a while
- Making me leave services forever

red face frowning with thumb pointing down
Clinical Record

What It Says
You have a right to look at your clinical record and other information about you.

What It Means
I can look at my chart, file or any paperwork about me. Some things that might be included in my chart are

- My picture
- My history
- Medical information
- Individual Services Plan
- Assessments and evaluations
- Important information like guardianship papers, Social Security information

binder with paper inside
Restriction of Rights

What It Says
If your rights are restricted, the person who is responsible for your services must tell you, your parents if you are under age eighteen, and your guardian if one has been appointed. In addition, the service provider must tell all persons or agencies that you choose to have told about the restriction. Justification for any restriction of your individual rights shall be documented in your individual record.

What It Means
If my rights are taken away, the agency must tell me and my legal guardian, if I have one. My guardian will help me decide if I want to tell other people or agencies. The agency must write in my plan:
• The right that was taken away
• The reason it was taken away
• What was tried before it was taken away
• How long it will be taken away
Exercising Your Rights

What It Says
You shall not be denied, suspended from or terminated from services or have services reduced for filing a grievance or for exercising any of your rights. See Form IL462-1202 for Your Right to Appeal.

What It Means
I have rights and can tell people at the agency if I don’t like something that is happening. If I am speaking up for my rights, the agency can’t
• Keep me from getting services
• Change services so I have less
• Make me leave services for a while
• Make me leave services forever

person with arms stretched out holding scale in each hand, scales are equal
Reporting

What It Says
You have a right to report any infringements of your rights to the human rights committee at your agency, the Independent Service Coordination agencies, the Department of Human Services, the Illinois Guardianship and Advocacy Commission, or to Equip for Equality. You also have the right to report any complaints or allegations of abuse, neglect, or exploitation as outlined below.

What It Means
I have a right to tell someone if my rights have been violated. I can tell

- the Human Rights Committee at my agency
- my Independent Service Coordinator
- the Department of Human Services
- Illinois Guardianship and Advocacy Commission
- Equip for Equality

I have a right speak up and speak out if my money or personal belongings have been taken, or if someone has hurt my body or my mind.

two people talking to each other
If I Have a Complaint

I have a right to speak up and speak out if I have a complaint about my services. If I have a legal guardian, my legal guardian, my family members or others can speak up and speak out if they have a complaint about my services. I have a right to ask for and get help from my agency to make a complaint. There are five (5) ways I can make a complaint:

1. Contact my Independent Service Coordination (ISC) agency. If I don’t know the name of the ISC agency, I have two choices to find out:

   o Use a computer and go to www.dhs.state.il.us/page.aspx?item=32253
     ▪ Under "Type," select "Developmental Disabilities"
     ▪ Under "County", select your county

   o Use a phone and call 1 (888) 337-5267 and enter my zip code to be connected to the closest ISC agency

   o I will hear from someone in two business days

2. Contact the Division of Developmental Disabilities

   o Use a phone and call 1 (888) 337-5267 or 1 (217) 785-6171 and ask to speak with staff

   o I will hear from someone in two business days
3. File a Report of Abuse or Neglect, or Exploitation

- For children under the age of 18 or for anyone residing in a Child Group Home or Child Care Institution, call the Department of Children and Family Services at 1 (800) 252-2873

- For adults age 18 and over, who reside in their own home or family's home, call the Adult Protective Services Hotline at 1 (866) 800-1409

- For individuals residing in a Community Integrated Living Arrangement (CILA) contact the Department of Human Services, Office of Inspector General at 1 (800) 368-1463

- For reporting incidents that occur at a Developmental Training site, contact the Department of Human Services, Office of Inspector General at 1 (800) 368-1463

- For individuals residing in a Community Living Facility (CLF), contact the Department of Public Health at 1-800-252-4343 or email at DPH.CCR@illinois.gov
4. **Contact the Guardianship and Advocacy Commission**, a state agency consisting of three divisions: Legal Advocacy Services, Human Rights Authority and the Office of the State Guardian. The Commission has offices around Illinois:

- **East Central Regional Office**  
  2125 S. First Street  
  Champaign, IL 61820  
  Phone: (217) 278-5577  
  Fax: (217) 278-5588

- **Peoria Regional Office**  
  401 N. Main Street, Suite 620  
  Peoria, IL 61602  
  Phone: (309) 671-3030  
  Fax: (309) 671-3060

- **Rockford Regional Office**  
  4302 N. Main Street, Suite 108  
  Rockford, IL 61103  
  Phone: (815) 987-7657  
  Fax: (815) 987-7227

- **Egyptian Regional Office**  
  #7 Cottage Drive  
  Anna, Illinois 62906-1669  
  Phone: (618) 833-4897  
  Fax: (618) 833-5219

- **West Suburban Regional Office**  
  Madden Mental Health Center  
  1200 S. First Street, P.O. Box 7009  
  Hines, IL 60141  
  Phone: (708) 338-7500  
  Fax: (708) 338-7505

- **Metro East Regional Office**  
  4500 College Avenue, Suite 100  
  Alton, IL 62002  
  Phone: (618) 474-5503  
  Fax: (618) 474-5517
5. **Contact Equip for Equality, Inc.**, an independent, not-for-profit organization that administers the federal protection and advocacy system to people with disabilities in Illinois. Equip for Equality, Inc., provides self advocacy assistance, legal services, education, public policy advocacy, and abuse investigations. The offices are located at:

- **Main/Chicago Office**
  20 N. Michigan, Ste 300
  Chicago, Illinois 60602
  Phone: (312) 341-0022 or (800) 537-2632
  TTY: (800) 610-2779
  Fax: (312) 341-0295

- **Central Illinois**
  1 West Old Capitol Plaza, Suite 816
  Springfield, IL 62701
  Phone: (217) 544-0464 or (800) 758-0559
  TTY: (800) 610-2779
  Fax: (217) 523-0720
- Northwestern Illinois
  1515 Fifth Avenue, Suite 420
  P.O. Box 276
  Moline, IL 61265
  Phone: (309) 786-6868 or (800) 758-0464
  TTY: (800) 610-2779
  Fax: (309) 797-8710

- Southern Illinois
  300 E. Main Street, Suite 18
  Carbondale, IL 62901
  Phone: (618) 457-7930 or (800) 758-6869
  TTY: (800) 610-2779
  Fax: (618) 457-7985

Equip for Equality’s website is www.equipforequality.org
I have a copy of my rights, and have asked questions and gotten answers. If I have a legal guardian, my legal guardian also has a copy of my rights, and has asked questions and gotten answers. A copy of this form will be put in my clinical record.

I have a right to ask for and get help from agency staff if I want to contact

- My Independent Service Coordination (ISC) agency
- Division of Developmental Disabilities
- Department of Children and Family Services
- Adult Protective Services
- Office of Inspector General
- Department of Public Health
- Guardianship and Advocacy
- Equip for Equality

__________________________  _______________________
My Signature                  My Printed Name

__________________________
Date I Signed My Name

__________________________  _______________________
My Legal Guardian’s Signature My Legal Guardian’s Printed Name

__________________________
Date My Legal Guardian Signed His/Her Name

Supplement to IL462-1201 (R-12-16) Rights of Individuals