

**State of Illinois  
Department of Human Services**



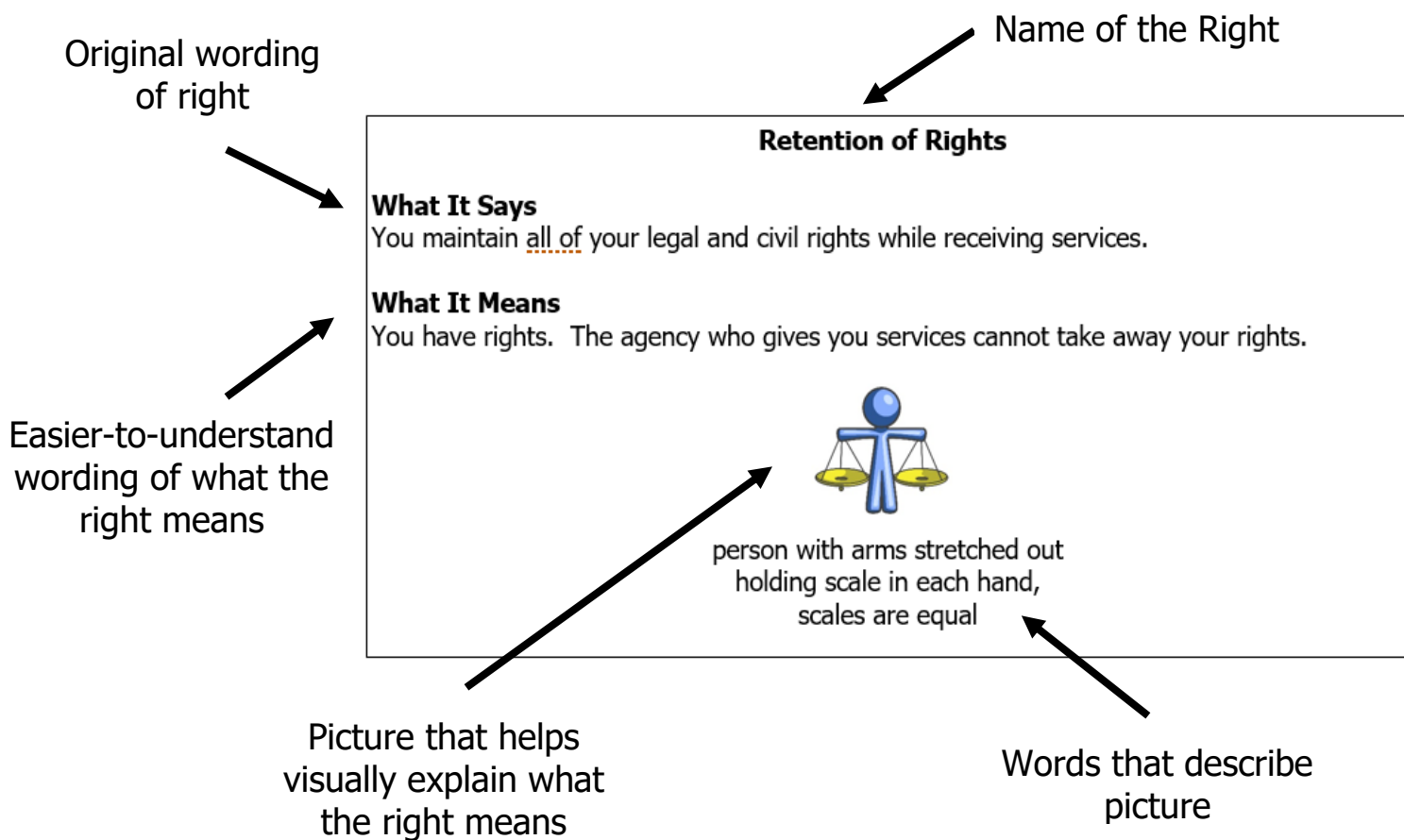
**Rights of Individuals  
in  
Medicaid Home and Community-Based Services  
Developmental Disability Waivers**

**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](http://www.dhs.state.il.us/onenetlibrary/12/documents/Forms/IL462-1201.pdf)



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

[www.illinois.gov/icdd](http://www.illinois.gov/icdd)



[www.selfadvocacyalliance.org](http://www.selfadvocacyalliance.org)

## 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

## 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 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.



person scratching head and  
looking at different directions  
to choose from

## 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.



person with a visual impairment with a walking stick and service dog



two Deaf people using sign language to talk



person in a wheelchair



people sitting around a table at a 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



person pulling another person's hair

#### 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



person yelling at another person

#### 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.



broken heart



sad face crying

## 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.



person running with a bag of money in hand



person sneaking away with a television under the arm

## 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.



person pointing a finger at another person



person making a fist and grabbing another person by the front of the shirt

## 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

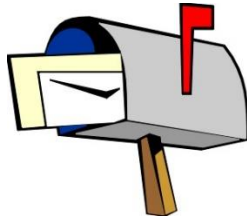
You have the right to communicate with other people in private, without obstruction or censorship by the staff. Communication by these means may be reasonably restricted, but only to protect you or others from harm, harassment, or intimidation.

### 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



telephone



two people ringing a doorbell at a front door



two people sitting at a table and talking

## Property

### What It Says

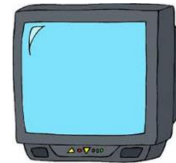
You have the right to receive, possess, and use personal property unless it is determined that certain items are harmful to you or others. When you stop receiving services from an agency, all lawful property must be returned to you.

### 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



television



cell phone



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.



person getting  
money at a bank

A screenshot of a bank statement from 'ANY BANK'. The statement includes account information and a table of transaction details. The table has columns for DATE, DESCRIPTION, DEBITS, CREDITS, and BALANCE. The transactions listed are: Balance brought forward (25.00), 6 May CDST High St (10.00), 8 May DCST Pet Care Pk (3.00), 11 May SACS Regular Times (40.00), 19 May CH07 (2.70), 19 May DD Gas & Co (10.00), and 22 May 00 TV Licence Company (21.00). The final balance is 28.30.

DATE	DESCRIPTION	DEBITS	CREDITS	BALANCE
	Balance brought forward			25.00
6 May	CDST High St	10.00		15.00
8 May	DCST Pet Care Pk	3.00		12.00
11 May	SACS Regular Times		40.00	52.00
19 May	CH07	2.70		49.30
19 May	DD Gas & Co	10.00		39.30
22 May	00 TV Licence Company		21.00	60.30

money report

## 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

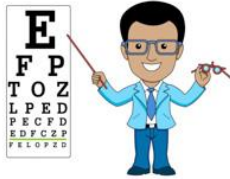
### What It Says

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



eye doctor



dentist



doctor



## 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

## 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



person moving a  
stack of boxes

## 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



person holding a yellow stop sign  
in one hand and holding up other  
hand to stop something

## 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 a 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:

- Use a computer and go to [www.dhs.state.il.us/page.aspx?item=32253](http://www.dhs.state.il.us/page.aspx?item=32253)
  - Under "Type," select "Developmental Disabilities"
  - Under "County", select your county



computer

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



telephone

- I will hear from someone in two business days

### 2. Contact the Division of Developmental Disabilities

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



telephone

- 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



telephone

- 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



telephone

- 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



telephone

- 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



telephone

- 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](mailto:DPH.CCR@illinois.gov)



telephone



computer



**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



phone book



telephone

- North Suburban Regional Office  
9511 Harrison Street, Room 335  
Des Plaines, Illinois 60016  
Phone: (847) 294-4264  
Fax: (847) 294-4263
  
- Chicago Regional Office  
160 N. La Salle Street, Suite S500  
Chicago, IL 60601  
Phone: (312) 793-5900  
Fax: (312) 793-4311
  
- Springfield Regional Office  
521 Stratton Building  
401 S. Spring Street  
Springfield, IL 62706  
Phone: (217) 785-1540  
Fax: (217) 524-0088

**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



phone book



telephone

- 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](http://www.equipforequality.org)



computer

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

