

Rights of People Who Have Guardians in Illinois and Get Medicaid Community Services

People with guardians have the right to make choices. Illinois laws say what a guardian can decide. Laws also say what a Medicaid community provider must do. This guide will help you understand these laws.

Making Decisions for a Person with a Guardian:

A guardian for personal decisions must help the person be as independent as possible. When helping a person make decisions, the guardian must:

FIRST, figure out what the person wants.

SECOND, support that decision unless the guardian has a reason to think it will cause the person "substantial harm." Example: the person wants to live with someone they just met on-line.

A guardian for money decisions must support the person in their choices unless spending the money will cause "substantial harm." Example: the person wants to give all their money to a scam phone caller.

If a guardian is not doing what they should, anyone can call or write the guardianship court for help. The courts' phone numbers and addresses are here: <https://www.illinoiscourts.gov/courts/circuit-court/circuit-court-clerks/>. The Court Order or "Letters of Office" will say what County the guardianship is in.

Laws Medicaid Community Providers Must Follow:

CILAs and Day Programs must follow laws too. These providers must give people choices. Examples:

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|---|---------------------------------|---------------------|
| ❖ Privacy in bedroom, including door lock | ❖ Have boyfriends / girlfriends | ❖ Learn about sex |
| ❖ Alone time | ❖ Travel or walk alone | ❖ Time in community |
| ❖ Pick job | ❖ Choose activities | ❖ Food choices |
| ❖ Choose friends | ❖ Volunteer | ❖ Buy things |

These are only some ways that people can make their own decisions each day, even with a guardian. If the guardian, person, or provider disagree, the ISC case worker may be able to help fix the problem. People with guardians can also call Equip for Equality for help if the problem is not fixed.

How to Find These Laws

Laws about Guardianship:

Illinois Probate Act (www.bit.ly/guardianship-laws):

755 ILCS 5/11a-17 (guardian of the person)

755 ILCS 5/11a-18(a-5) (guardian of the estate - money)

755 ILCS 5/11a-20(b) (contact court about problems)

Laws Providers Must Follow:

Illinois Mental Health and Developmental Disabilities Code / Rules (www.bit.ly/provider-laws-1 and www.bit.ly/provider-laws-2):

405 ILCS 5/2-100 405 ILCS 5/2-101.1

405 ILCS 5/2-102 405 ILCS 5/2-103

405 ILCS 5/2-104 405 ILCS 5/2-201

59 Ill. Adm. Code 115.250

Medicaid Home and Community Based Settings Rule (<http://www.bit.ly/medicaid-laws>):

42 C.F.R. § 441.530

Contact for Independent Service Coordination (“ISC”) Agencies

If you don't know who your ISC is, go to <https://www.dhs.state.il.us/page.aspx?module=12>, and for “Select an Office Type” choose “Developmental Disability Services.”

You can also call the Illinois Department of Human Services Customer Help Line to find out who your ISC provider is at 1-800-843-6154.

Contact for Equip for Equality (Main Office)

20 North Michigan Ave., Suite 300

Chicago, IL 60602

1-312-341-0022 (Voice)

1-800-537-2632 (Voice)

1-312-800-0912 (Fax)



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