

LIVING / WELL

Healthy, Safe and Connected



LET'S TALK ABOUT RIGHTS: A Guide for Providers

V.0623



WISCONSIN BOARD FOR PEOPLE
WITH DEVELOPMENTAL DISABILITIES

This project was supported, in part by grant number 90DNIQ0004-01-00, from the U.S. Administration for Community Living, Department of Health and Human Services, Washington, D.C. 20201. Grantees undertaking projects with government sponsorship are encouraged to express freely their findings and conclusions. Points of view or opinions do not, therefore, necessarily represent official ACL policy.



LET'S TALK ABOUT RIGHTS

Wisconsin Board for People with Developmental Disabilities' Rights Toolkit

Table of Contents

INTRODUCTION	2
WHY ARE RIGHTS IMPORTANT?	3
WHAT RIGHTS ARE PEOPLE WITH DISABILITIES ENTITLED TO?	4
PRINCIPLES FOR ALL RIGHTS	5
WHAT DO RIGHTS ENTAIL AND HOW TO HELP PEOPLE EXERCISE THEM	6
EQUAL PROTECTION AND DUE PROCESS	8
CONTROL OF MONEY	9
FREEDOM OF SPEECH AND EXPRESSION	12
FREEDOM OF FAITH BELIEFS	14
CITIZENSHIP AND THE RIGHT TO VOTE	16
RIGHT TO PRIVACY	18
FREEDOM OF ASSOCIATION	20
FREEDOM FROM HARM AND CRUEL AND UNUSUAL PUNISHMENT	22
RIGHT TO POSSESSIONS	24
EQUAL EDUCATION OPPORTUNITY	26
EQUAL EMPLOYMENT OPPORTUNITY	28
ACCESS TO HEALTHCARE	30
LEISURE AND REST	32
RIGHTS GUARANTEED UNDER THE HCBS SETTINGS RULE	34
RESOURCES AND REFERENCES	35
STATE OF WISCONSIN RESOURCES	35
OTHER RESOURCES	36



The 'Let's Talk About Rights' Toolkit was developed by CQL | The Council on Quality and Leadership, with support, in part, from grant number 90DNIQ0004-01-00, from the U.S. Administration for Community Living, Department of Health and Human Services, Washington, D.C. 20201.

INTRODUCTION

Rights are things that people can (or should be allowed to) have or to do. Sometimes people with disabilities have access to fewer or limited rights. This may be due to discrimination, low expectations¹, and even laws (both current and outdated laws) that may limit the rights of people with disabilities.

We know that when people understand and use their rights, they have better lives. This toolkit is an effort to teach people on rights of people with disabilities that are protected by state, federal, and international laws, the US constitution, and various court decisions. This toolkit provides information to learn about, understand, advocate for, and exercise personal rights and freedoms.



How can people exercise their rights if they don't know what they are?

Patrick, Self-Advocate



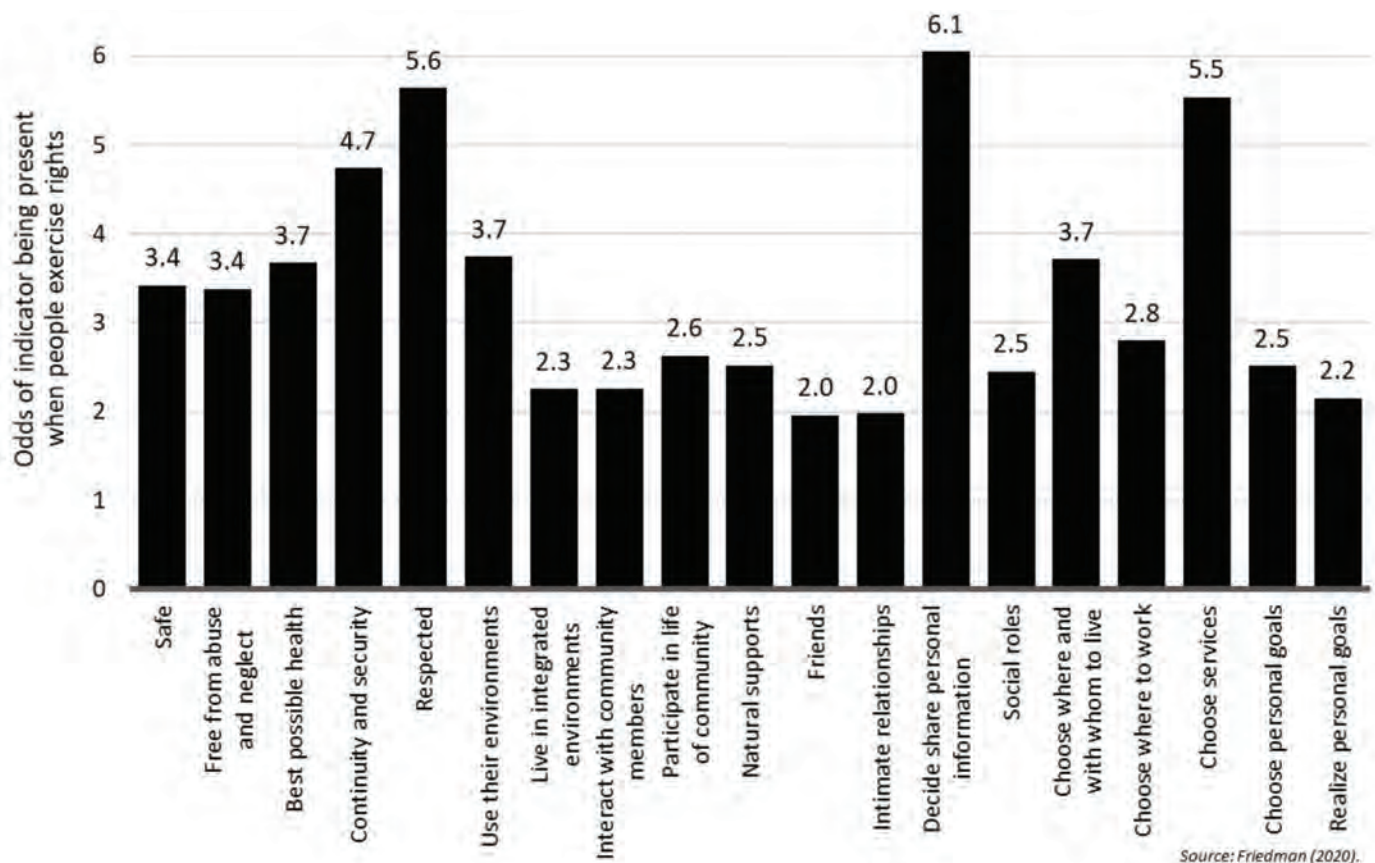
Check out our Know Your Rights Video Series on the Self-Determination Channel!

¹For more information, view CQL's webinar Modern Ableism and Disability Prejudice. <https://www.c-q-i.org/resources/webinars/modern-ableism-and-disability-prejudice/>

WHY ARE RIGHTS IMPORTANT?

Research shows exercising rights greatly improves people with developmental disabilities' quality of life. CQL | The Council on Quality and Leadership studied 2019 Personal Outcome Measures® interviews from 1,250 people with disabilities. They found that people who exercised rights had almost twice as many quality of life outcomes present compared with people who didn't exercise rights. In fact, exercising rights greatly increased the chances that all other outcomes were present (see figure below). For example, people who exercised rights were twice as likely to have friends. They were 3 times more likely to participate in community life and 6 times more likely to choose their own services.

IMPACT OF RIGHTS ON QUALITY OF LIFE OUTCOMES



Research by CQL | The Council on Quality and Leadership has also found the huge impact personalized organizational supports can have on people with disabilities exercising rights. In fact, people with disabilities are 27 times more likely to exercise their rights when organizations have supports in place. By learning about people's wishes and desires related to rights, and supporting people to exercise their rights, organizations help promote people's quality of life.

This Rights Toolkit covers just some of the rights people with disabilities are entitled to. We talk about what the right means, the laws, rulings, etc. that grant these rights, and why these rights are important. Then we discuss what supporters can do to assist and what people with disabilities can do.

WHAT RIGHTS ARE PEOPLE WITH DISABILITIES ENTITLED TO?

People have many rights that are guaranteed by the U.S. Constitution, state and federal laws, and international human rights agreements. Some of these include:

- Equal protection and due process.
- Control over their own money as property.
- Freedom of speech and expression.
- Right to faith beliefs.
- Right to vote.
- Right to privacy.
- Right to free association.
- Freedom from cruel and unusual punishment.²
- Right to buy and sell personal items including their own home.
- Right to education.
- Equal employment opportunities.
- Right to dignity and respect.
- Right to rest and leisure.
- Right to access to healthcare.



In addition, people receiving Medicaid Home and Community Based (HCBS) services and supports are entitled to the following rights:

- Choice of where they live (from options including non-disability settings) and who they live with.
- Choice of services and who provides them.
- Individual rights of privacy, dignity and respect, and freedom from coercion and restraint.
- Autonomy and independence in making life choices.

If you live in a provider owned or controlled HCBS residential setting, you also have the:

- Right to have visitors at any time.
- Right to access food at any time.
- Right to access the community.
- Right to have a lease or other legally enforceable agreement providing similar protections.
- Right to privacy in their unit including lockable doors and choice of roommates.
- Right to furnish or decorate the unit.
- Right to control their own schedule.
- Right to a physically accessible setting.

²WI Administrative Code DHS Chapter 94, permits the use of medications, isolation, seclusion, physical restraints, electroconvulsive therapy, and drastic treatment under certain conditions. Disability Rights Wisconsin advocates to reduce the use of involuntary commitments and admissions and seclusion and restraint <https://www.disabilityrightswi.org/resources/misuse-of-seclusion-and-restraint/>

PRINCIPLES FOR ALL RIGHTS

All people have a duty to obey the law and are responsible for the decisions and actions they make. Sometimes life decisions involve risk, and this can be a great learning opportunity. Some things to consider when thinking about risk include:

- Life experiences come with risk.
- People will have both success and failure throughout their lives.
- Support staff and services should encourage people to make their own informed choices.
- The right to take reasonable risks is crucial for dignity and self-esteem.
- The balance between over-protection and risk is vital for people's self-image.
- People should have freedom to make decisions and choices that may expose them to a level of risk.
- To avoid risk at all cost just to keep people safe may infringe on rights and result in lost opportunities.
- Too much caution by staff, caregivers, and others can prevent growth and learning.

The principle of dignity and choice is about:

- Respecting and valuing the knowledge, abilities, and experiences that people with disabilities have.
- Supporting them to make choices about their lives.
- Enabling each person to live the life they want to live.

Supporters should also always presume competence. This means believing people are capable, that they do understand you even if they do not outwardly show you that they do. Presuming competence requires one to:

- Think about and talk to the person with a disability as you would any other person.
- Assume that a person with a disability has the capacity to think, learn, and understand.
- Understand that just because a person has been given a diagnosis or label, it does not mean they cannot progress and succeed.
- Believe people are capable of great things!
- Use respectful language using people's preferred names, pronouns, and preferred disability language.
- Enhance people's self-image.
- Focus on privacy, informed choices, feelings, and ideas.
- Look for ways to lessen or decrease risk, while knowing that life is full of risk and many activities may involve risk.

In addition, to protect their rights, people with disabilities should and are entitled to:

- Speak up and be heard if they have concerns.
- Complain or appeal if something is not fair.
- Use the justice system (file a police report if property is stolen or if they are harmed, etc.), if they choose.
- Let people know if they do not agree with the support or the reason for the support.
- Learn about their rights and help teach others, including staff, about them.
- Help others protect their rights.

- Contact a lawyer if they need legal advice or help.
- Ask the court to restore rights or settle a dispute.
- Invite people the person chooses to planning meetings, including attorneys or others.
- Receive adequate due process (includes having their attorney or representative present) regarding any rights restriction placed on them either by the courts or a provider.
- Be provided with information and education about court access and legal services.

WHAT DO RIGHTS ENTAIL AND HOW TO HELP PEOPLE EXERCISE THEM

EQUAL PROTECTION AND DUE PROCESS

All citizens have the right to due process and equal protection under the law in the United States Constitution (Amendment 14). This prohibits the state (the government) from depriving anyone of life, liberty, or property without due process of law.

Equal protection safeguards people from being discriminated against because of certain characteristics, including having a disability.

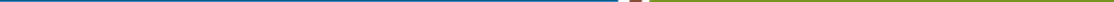
Due process is all about protecting people when their individual rights are reduced, limited, or restricted. The

process is normally used in the legal system to ensure the state respects all the legal rights owed to people. However, many states require that people with disabilities receive a different type of due process, instead of using the court system. This independent review committee is sometimes called a Human Rights Committee. Human Rights Committees (HRCs) are responsible for making sure safeguards are in place, including the person being informed prior to any restriction or modification being discussed or put into place. HRCs also make sure the person has the ability to object to the limitation or appeal the decision. HRCs also can conduct hearings in which the person can respond to or defend themselves. People have the right to consent to any rights restriction or limitation, and the right to go through a formal independent review process, such as the court system or other review body like a Human Rights Committee.



Human Rights Committees

It is considered best practice to have external members (i.e., members that do not work for (or are not connected with) the provider agency) take an active role in these committees. HRCs should meet on a regular basis and should actively involve the people with disabilities whose rights are being discussed in these decisions. For more information on effective HRCs visit <https://www.c-q-l.org/resources/webinars/a-working-and-effective-human-rights-committee/>.

This image shows a blank sheet of white paper with horizontal ruling lines. The lines are evenly spaced and run across the width of the page. There are no margins, text, or other markings on the paper.

ADDITIONAL PROTECTIONS UNDER THE HCBS SETTINGS RULE

For people getting services and supports through a Medicaid HCBS waiver in a provider operated setting, there are other requirements the federal government has outlined to protect their rights. This is especially important when rights are restricted.

For anyone receiving HCBS services, when rights are restricted, the following eight requirements must be met:

- Base the restriction or modification on a specific, personalized need (i.e., the restriction must be tailored for the person – not just because the person has a certain diagnosis or lives in a specific home).
- Document in the person-centered plan that positive interventions have been tried but have not worked.
- Document less intrusive methods of meeting the need have been tried but did not work (i.e., do not jump to the most intrusive or restrictive intervention)!
- Include a clear description of how the restriction is directly proportionate to the specific need (e.g. changes or fades over time as improvements are made or a situation changes. We know that some people are on restrictions for things they did many years ago. Any rights restriction or limitation must be necessary now, and not just because a person did something 20 years ago!)
- Keep measuring if the restriction is helping.
- Include set time limits for regular reviews to decide if the restriction is still needed, or if it can be stopped.
- Get informed consent (permission) for the restriction from the person.
- Assure the limitation/restriction will cause no harm.

When it comes to equal protection and due process, agencies should support people to:

- Understand what a restriction is.
- Understand how restrictions are restored (how they get their rights back). Do this without expecting perfection – people with disabilities should not be held to a higher standard than anyone else!
- Attend and speak up at any meeting where the restrictions are discussed.
- Learn new skills so their rights can be restored.
- Train staff on due process and rights restrictions.
- Ensure Human Rights Committees actively promote and protect people's rights.

As a supporter of people with disabilities, you can help by:

- Giving information about rights restrictions or limitations.
- Making sure people with disabilities are not discriminated against based on their disability or other category such as race, age, sexual orientation, or gender identity.
- Assisting people with disabilities to learn about Supported Decision Making (a model for people with disabilities to exercise and/or restore rights) and supporting them in the process if they want; see more information at: <https://wi-bpdd.org/index.php/supporteddecision-making/>.
- Making sure that any rights restrictions and limitations are reviewed by an objective, 3rd party.

To protect their rights, people with disabilities should:

- Speak up for themselves!
- Learn about what rights they are entitled to and how to protect them.
- Learn about due process and what to do if rights are limited or removed.
- Be present and active at any meetings that involve them and their services.
- Invite people they want to their meetings.



EQUAL PROTECTION AND DUE PROCESS

1. What agency policies and expectations exist to support people to exercise rights related to equal protection and due process?

2. How are staff actively supporting people in this area?

3. Three ways we could improve our policies and supports in this area:

CONTROL OF MONEY

All people, including people with disabilities, have the right to control their own money and make decisions on how to spend it. Though the US Constitution and the United Nation's Declaration of Human Rights do not talk about money specifically, they do address the right to own property. Money as a form of property is often taken for granted. Yet, most people with disabilities have restrictions around exercising this right. Often people with disabilities have representative payees and receive an "allowance" rather than free access to their money. Also, many people with disabilities must track their spending and provide receipts for things they buy.

When it comes to control of money, agencies should support people to:

- Do their own banking (in person and online).
- Have regular, accurate, and clear accounting of their finances/money.
- Decide who keeps and holds their money, check book, and bank cards.
- Make their own decisions about the amount of money they carry.
- Decide how much of their money to put in their bank account and how much to keep out.
- Choose a bank that meets their needs and preferences.
- Presume competence and believe that people can, with the proper support, control their money.



As a supporter of people with disabilities, you can help by:

- Not judging people about how their money is spent.
- Supporting people to manage their funds (though only to the extent necessary).
- Helping people pick safe storage options for any cash or credit cards they keep in their home, if needed.
- If people are banking online, staff should help people to safely file their electronic information.
- Be informed and educated about sources of money like SSI (Social Security Income), SSDI (Social Security Disability Income) and other sources like trust funds.
- Reviewing and questioning any agency policies or procedures that may limit people's control over their own money.

To protect their rights, people with disabilities should:

- Learn about their right to control their own money, and any restrictions they may have.
- Understand what a representative payee does and what the limits are.
- Decide, with support as needed, how they want their finances handled.
- Know their rights around choosing a bank, a rep payee (if wanted or needed)³, and how to responsibly handle benefit income, earned income, and gifted income.
- Learn about budgets and expenses.

CONTROL OF MONEY

1. What agency policies and expectations exist to support people to exercise rights related to control of money?

How are staff actively supporting people in this area?

Three ways we could improve our policies and supports in this area:

³For more information view Money, Money, Money, My Rep Payee Manages That: <https://www.c-q-l.org/resources/webinars/money-money-money-my-rep-payee-manages-that/> .

FREEDOM OF SPEECH AND EXPRESSION

All people have the right to think and say what they want, and not to be stopped from doing so. Sometimes people need encouragement, support, and/or technology to exercise this right. While the concept is often related to speaking in public forums, this right also applies to people's right to speak privately with others they choose (and can overlap with their right to privacy). Freedom of speech and expression is a constitutional right and is also found in the United Nation's Declaration of Human Rights.

When it comes to freedom of speech and expression, agencies should support people to:

- Have access to the phone, internet, film, newspapers, television, social media, etc. (and in accessible formats).
- Be able to express opinions, thoughts, and ideas without fear of "payback," or retaliation.
- Be able to hold private conversations with people they want.
- Know they can express themselves without fear of retaliation.

As a supporter of people with disabilities, you can help by:

- Listening to what people have to say.
- Making sure the people you support have access to any AAC or other communication tools (e.g., American Sign Language, picture books, communication devices, voice services, etc.) they need.
- Supporting people to attend and participate in all meetings (support, behavior, human rights, etc.) about themselves.
- Providing training and support in speaking up and self determination.
- Supporting people to attend and participate in advocacy activities if they choose.

To protect their rights, people with disabilities should:

- Speak up!
- Learn about the self-advocacy movement and any groups in their area.
- Express their thoughts and ideas.
- Accept responsibility for what they do and say.
- Learn to listen to others and hear what they are saying.



FREEDOM OF SPEECH AND EXPRESSION

1. What agency policies and expectations exist to support people to exercise rights related to freedom of speech and expression?

2. How are staff actively supporting people in this area?

3. Three ways we could improve our policies and supports in this area:

FREEDOM OF FAITH BELIEFS

All people are free to choose any belief and to not be discriminated against based on their beliefs or religious opinions. People can also choose not to practice a religion. The US Constitution forbids the government from limiting the free exercise of religion.

When it comes to freedom of religious expression, people with disabilities have the right to:

- Express their religious beliefs.
- Practice their religious beliefs by going to religious services, praying, wearing clothes that show their beliefs.
- Receive and participate in faith-based rituals (e.g., sacraments, Shabbat, Sawm-fasting, etc.) if desired.
- Become a formal member of a religious group or community, join the choir, volunteer time, and donate money, if they desire.
- Eat foods or drinks that are a part of belief system (e.g., Kosher foods, vegetarian foods, etc.).
- Decide to not participate in any religious or spiritual activity.

When it comes to freedom of religious expression, agencies should support people to:

- Learn about different religious and spiritual options and opportunities.
- Ensure staffing and transportation are available to assist people to participate in religious and spiritual activities and practices.

As a supporter of people with disabilities, you can help by:

- Assisting people to attend services of their choice (i.e., not just a service that is convenient for staff or the home).
- Respecting that other people's beliefs may differ from your own. Do not try to stop people from doing something because of your own beliefs or religion.
- Making sure people are not coerced or manipulated in the name of religion. For example, do not say things like you're going to go to hell if you do that.

To protect their rights, people with disabilities should:

- Learn about different religions and beliefs, if desired.
- Speak up when they want to participate or express their religious beliefs.
- Respect other's beliefs and opinions.





FREEDOM OF FAITH BELIEFS

1. What agency policies and expectations exist to support people to exercise rights related to freedom of faith beliefs?

2. How are staff actively supporting people in this area?

3. Three ways we could improve our policies and supports in this area:

CITIZENSHIP AND THE RIGHT TO VOTE

Voting is a United States constitutional right. Most citizens have the right to vote if they are over 18, are registered, and have not been convicted of a felony. However, many states override this right for people with disabilities. In the United States, the federal Voting Rights Act requires that any eligible voter who requires support (due to disability, or if they cannot read or write) may be helped by a person of the voter's choice.

In Wisconsin, some people cannot vote. People can lose their right to vote if:

- A judge removes that right under the guardianship process.
- A judge has found a person to be unable to understand the voting process.
- Or if a person has been convicted of a felony and has not completed probation or parole.
 - For more information visit the Wisconsin Disability Rights website:
<https://www.disabilityrightswi.org/act/vote/>.
 - For more information on the impact of guardianship on voting in Wisconsin, view
<https://disabilityvote.org/wp-content/uploads/2018/08/Guardianship-and-voting-English-ACC.pdf>. If you are under guardianship, your Determination and Order form will include information about your right to vote.

When it comes to citizenship and the right to vote, agencies should support people to:

- Learn about registering to vote: <https://disabilityvote.org/>.
- Find unbiased information about people running for office, including ones that align with people's own belief systems (<https://www.isidewith.com/>).
- Restore their right to vote if this right has been restricted

As a supporter of people with disabilities, you can help by:

- Supporting people to cast their vote.
- Getting people to the polling site, or supporting them to fill out an absentee ballot, when needed.
- Making sure people's opinions are respected, and nobody is judged or treated unfairly due to their political views or opinions.

People with disabilities should:

- Speak up for what they believe in!
- Learn about their right to vote and understand when this right might be taken away.
- Remember that nobody should tell them how to vote – it is their own choice!
- Learn about political issues that impact them and others as citizens and community members.
- Peacefully march and protest to express an opinion about an issue.



CITIZENSHIP AND THE RIGHT TO VOTE

1. What agency policies and expectations exist to support people to exercise rights related to citizenship and the right to vote?

2. How are staff actively supporting people in this area?

3. Three ways we could improve our policies and supports in this area:

RIGHT TO PRIVACY

Citizens have certain rights when it comes to privacy. Some laws protect people's personal information, especially their health information (e.g., HIPAA). Constitutional amendments also protect privacy of beliefs (1st Amendment) and privacy against unreasonable searches (4th Amendment). International declarations address the issue as well. For example, The United Nations Declaration of Human Rights states that no one has the right to interfere with a person's privacy, family, or home. Privacy is also addressed in the Medicaid HCBS Settings Rule which ensures individual rights of privacy (and dignity and respect) for people receiving HCBS services. The settings rule states that people receiving HCBS services in provider run settings are guaranteed the right to have visitors at any time, have keys to their home, and have locks on their doors⁴. Finally, it is addressed in state policies including the State of Wisconsin's Civil Rights Statutes and Administrative Codes.

When it comes to privacy, best practice includes people with disabilities being able to:

- Receive and open their own mail.
- Keep personal belongings safely.
- Receive, make, and send phone calls, social media posts, email privately.
- Have private conversations or communication with friends, family, and staff.
- Spend time alone with friends and family when they wish.
- Have people knock on their door and wait for an answer before entering their home and/or room.
- Be alone without someone monitoring or limiting their privacy. This includes monitors, cameras, bed checks, line of sight vision, etc. When these things exist, there must be due process (see page 7).

When it comes to privacy, agencies should support people to:

- Keep their information private and confidential.
- Know what information the agency keeps about them, where it is stored, and who has access to it.
- Have access to private spaces for hygiene and other personal care tasks
- Have keys to their home and locks on their doors.

As a supporter of people with disabilities, you can help by:

- Helping to maintain the confidentiality of records, including financial records, that you have access to.
- Only releasing private information with informed, written consent and for a specific time and purpose.
- Keeping personal information secure and not posted in public places.
- Supporting people to complete personal hygiene practices in private, and when people wish.
- Teaching people with disabilities about privacy in the home, school, work, and online settings.

People with disabilities should:

- Learn about their right to privacy and how to protect it.
- Let others know when they need some privacy.
- Speak up when they feel their privacy is not being respected.
- Be a part of any decisions that are made about them and their health, finances, and other important life areas.
- Respect other's privacy and confidentiality (e.g., knock and wait for permission to enter another person's room; ask for permission to use or borrow someone else's things).



RIGHT TO PRIVACY

1. What agency policies and expectations exist to support people to exercise rights related to privacy?

2. How are staff actively supporting people in this area?

3. Three ways we could improve our policies and supports in this area:

⁴ For more information on locks in residential settings in Wisconsin see <https://www.carewisc.org/wp-content/uploads/2018/07/Frequently-Asked-Questions.pdf>

FREEDOM OF ASSOCIATION

All people (with or without) disabilities have the right to choose with whom to spend time or associate with. The United States Constitution and the United Nation's Declaration of Human Rights state that people have the right to peaceably assemble (meet in groups). This could be for political purposes (such as joining a civil rights group) or for personal reasons (e.g., choosing who you want to spend time with). Often people with disabilities are denied access to people without disabilities (possibly due to "over-protection") or have restrictions around guests or relationships. However, for people receiving Medicaid HCBS services and supports in a provider operated setting, some specific rights are guaranteed including the right to have visitors at any time.

When it comes to freedom of association, best practice includes people with disabilities being able to:

- Meet with people they choose.
- Have visitors at any time (if they receive HCBS services).
- Establish and maintain friendships.

When it comes to freedom of association, agencies should:

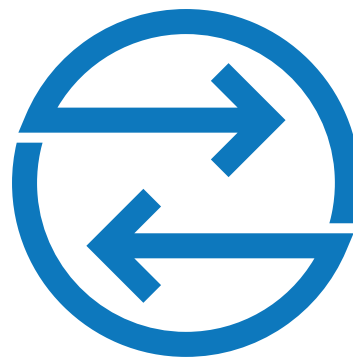
- Make sure policies do not exist that limit visitation.
- Ensure people receiving supports have access to telephones and computers to connect with friends and family.
- Ensure policies do not include restrictions on freedoms to associate (volunteers, visiting policies, etc.).

As a supporter of people with disabilities, you can help by making sure the people you support can:

- Spend time with friends and family where and when they want.
- Decide when guests visit.
- Talk on the phone and use virtual apps or platforms (like skype or Zoom) with friends and family if desired.
- Meet and interact with others in their community, such as neighbors, civic groups, friends, local vendors, clerks, etc.
- Date and have intimate relationships.
- Join groups or clubs based on personal values and interests.
- Access groups or activities (e.g., ensure they have transportation and funds available).

People with disabilities should:

- Understand that friendships are reciprocal (a two-way street).
- Respect other's beliefs and opinions, even when they are different from their own.
- Take responsibility for your words and actions.
- Explore new activities and groups.





FREEDOM OF ASSOCIATION

1. What agency policies and expectations exist to support people to exercise rights related to freedom of association?

2. How are staff actively supporting people in this area?

3. Three ways we could improve our policies and supports in this area:

FREEDOM FROM HARM AND CRUEL AND UNUSUAL PUNISHMENT

The right to be free from cruel and unusual punishment is guaranteed by the US Constitution. While the legal definition of “cruel and unusual” varies from state to state, it normally means punishments that are extreme compared to the crime. **The UN Declaration of Human Rights** states that “no one shall be subjected to **torture** or to cruel, inhuman or degrading treatment or punishment.” The US Supreme Court has also ruled that punishments should not reduce human dignity, must not be arbitrary (or random), unnecessary, or generally something that is not acceptable in society (**Furman v. Georgia, 408 U.S. 238, 1972**). People should not be subjected to actions by anyone, which cause them physical or emotional harm. Use of people’s resources, possessions, or work without fair reimbursement (payment) should not be allowed. No one should be subjected to verbal, physical, sexual, or psychological abuse. Also, people should not be neglected. In other words, it is unacceptable (there should be zero tolerance) for any human to suffer abuse, neglect, mistreatment, or exploitation.

When it comes to freedom from harm and cruel and unusual punishment, people with disabilities should:

- Not be bullied, mistreated, or ignored.
- Feel safe in their own home (e.g., people should not be intimidated or hurt by housemates or staff; property should be safe from theft).
- Be free from abuse, neglect, mistreatment, and exploitation (ANME).
- Not be restrained⁵ and if restraint is used, due process is required (see page 7 of this toolkit).
- Have free access to their money, know how much money they have, and know how it is spent (prevent financial exploitation).

When it comes to freedom from harm and cruel and unusual punishment, agencies should:

- Establish clear policies and procedures around abuse, neglect, mistreatment, and exploitation (i.e., what they are, clearly state they will not be allowed).
- Ensure all people who get supports are trained in, and understand, what ANME is and what to do if they (or someone they know) are a victim of ANME.
- Make sure systems are in place to collect and analyze any data related to ANME, including injuries of unknown origin.
- Train all staff to prevent, detect, and report claims of abuse, neglect, mistreatment, and exploitation.
- Ensure thorough, appropriate, and prompt responses to confirmed cases of ANME.
- Support the victim of ANME.

As a supporter of people with disabilities, you can help by:

- Teaching the people you support about their rights.
- Helping to prevent abuse, neglect, mistreatment, and exploitation (ANME).
- Learning about required reporting and your organization’s ANME policies and procedures.
- Listening to, and providing support to, people who share they have been a victim of abuse or neglect.
- Making sure you do not dismiss their trauma.
- Making sure the people you support have legal safeguards available (such as a Human Rights Committee, ombudsman, or the court system, when needed.)
- Treating the people you support with dignity and respect.

People with disabilities should:

- Learn what abuse, neglect, mistreatment, and exploitation mean.
- Learn who to tell if they are harmed.
- Learn what their rights are and how to protect them.
- Treat others with dignity and respect.

A good resource about this right for people with disabilities and their supporters is called: ***From Inquiry to Insight: Guided Discussion for Preventing Abuse and Neglect of Persons with Cognitive Disabilities*** by Art Dykstra and Amy Tambor.

FREEDOM FROM HARM AND CRUEL AND UNUSUAL PUNISHMENT

1. What agency policies and expectations exist to support people to exercise rights related to freedom from harm and cruel and unusual punishment?

2. How are staff actively supporting people in this area?

3. Three ways we could improve our policies and supports in this area:

⁵The use of various restraints is allowed under Wisconsin Administrative Code DHS Chapter 94. The use of restraint, however, can often lead to abuse or an increase in the very behaviors it is trying to reduce. Research also shows it can be traumatic for staff that have to use it. Often “challenging” behaviors are a form of communication, so attempts to de-escalate and other preventative measures should be prioritized.

RIGHT TO POSSESSIONS

The United States Constitution and the United Nations Declaration of Human Rights note people's belongings are private and can only be used with the owner's permission. People have the right to select, obtain, and use their possessions when they wish (this includes money which is covered in an earlier section). Buying, owning, and selling property such as land or housing are also a part of this right.

When it comes to their right to buy, sell, and use property, agencies should support people to:

- Manage their own money and purchase things (possessions).
- Freely access their personal items, including food and clothing.
- Shop for, and safely store, their property, as desired.
- Have proper clothing for different temperatures, activities, age group, and cultural norms.
- Access personal belongings without asking permission (e.g., property, clothes, hygiene supplies, food, etc.).
- Decide who borrows or uses their things.
- Get protection or insurance for personal belongings.
- Sign a lease and have tenant rights including protections from unlawful eviction and discrimination, when renting a home or living in a provider operated HCBS setting.
- Learn about owning a home including financial options and requirements.



As a supporter of people with disabilities, you can help by:

- Supporting people to learn money management skills.
- Respecting their decisions on what to buy and own, and not judging them on their decisions.
- Help people access the grocery store and clothing stores, etc. (including on-line).
- Supporting people to learn about and understand laws about leasing, renting, or buying property and the pros and cons of each option.
- Assisting people to find information on auto, homeowner's, and renter's insurance.
- Educating people on building credit and understanding national credit scores.
- Helping people to know when they might need a financial or legal advisor.
- Ensure due process if person has any restrictions or limitations in accessing their possessions.

People with disabilities should:

- Buy things they choose.
- Get rid of things they do not use or no longer want.
- Decide who uses their things.
- Protect their possessions (and buy insurance if needed).
- Learn about their rights if they rent a home (e.g. their lease).
- Learn about owning a home.



RIGHT TO POSSESSIONS

1. What agency policies and expectations exist to support people to exercise rights related to possessions?

2. How are staff actively supporting people in this area?

3. Three ways we could improve our policies and supports in this area:

EQUAL EDUCATION OPPORTUNITY

In 1975 the Education for All Handicapped Children Act (which was renamed in 1997 as the Individuals with Disabilities Education Act (IDEA)) changed public education. The Act requires all children with disabilities have the right to a free, appropriate public education. All children can benefit from education and training. Students with disabilities must be given reasonable accommodations to access any public school, including universities and community colleges.

When it comes to education, people with disabilities have a right to:

- A free, appropriate public education (between the ages of 3 – 21).
- An Individualized Education Plan (IEP) or 504 Plan, when needed.
- Not be discriminated against due to their disability.

When it comes to education, agencies should support people to:

- Get any technology (such as communication devices, software, and smart technology) that will support them in their education.
- Receive any accommodations they need to learn and succeed.
- Be a part of their Individualized Education Plan meeting, or Section 504 meeting, when applicable.
- Pursue lifelong learning.

As a supporter of people with disabilities, you can help by:

- Helping them to use school buses and public transportation to attend classes.
- Working with them to find tutors or mentors, if needed.
- Teaching them about local social and community services, such as the local library or civic groups.
- Promoting continued education (for example, General Education Diploma (GED), continuing education, or certifications, etc.).
- Recognizing that many tests are culturally and/or racially biased, and advocating that inappropriate testing not be used to discriminate against people or limit their opportunities.
- Supporting people to advocate for reasonable accommodations for educational opportunities.
- Supporting people to only answer essential questions about their disability to request accommodations.

People with disabilities should:

- Learn about disclosure requirements for obtaining services.
- Learn about their rights under IDEA and the ADA.
- Ask for support to help them get the most out of their education.
- Learn about school requirements (e.g. what time classes start, what assignments they must complete).
- Research and learn about different topics they are interested in.
- Ask for accommodations if they need them to succeed





EQUAL EDUCATION OPPORTUNITY

1. What agency policies and expectations exist to support people to exercise rights related to education?

2. How are staff actively supporting people in this area?

3. Three ways we could improve our policies and supports in this area:

EQUAL EMPLOYMENT OPPORTUNITY

The United Nations Declaration of Human Rights says that all people have the right to work, to free choice of employment, to just and favorable conditions of work, and to protection against unemployment. Also, it states that everyone has the right to equal pay for equal work without any discrimination. The Americans with Disabilities Act (ADA; 1990) provides civil protections for people with disabilities and prohibits employment discrimination based on a disability. For example, where there are 15 or more employees, the employer is expected to provide “reasonable accommodations” to support people with disabilities to do the job they are qualified to do. Work, or post-secondary education, should be the first option for people of working age receiving services. The 2014 United States Workforce Innovation and Opportunity Act (WIOA) helped to expand people with disabilities’ employment opportunities.

When it comes to employment, agencies should support people to:

- Choose where they work.
- Earn at least federal or state minimum wage.
- Have a choice about their services and supports and who provides them.
- Have personalized supports, and have staff trained adequately in the process.
- Have an employment coach or mentor, if needed.
- Have reasonable accommodations (e.g., improved accessibility in the office, flexible hours, reserved parking, assistive technologies, job restructuring, personal assistance).
- Be provided the opportunity to seek competitive employment.
- Support people to retire when they reach that age.

As a supporter of people with disabilities, you can help by:

- Helping people with job searches, applications, and interviews.
- Supporting people with disabilities to get the accommodations they need to succeed at work.
- Helping increase people’s exposure to various types of jobs and careers.
- Educate people about the Workforce Innovation and Opportunity Act (WIOA).
- Assist people to keep their employment (e.g., ensure their access to transportation or teach them to use public transportation, if available).
- Support people to advocate for competitive wages and raises.

People with disabilities should:

- Learn what is expected of them as an employee (e.g., what time to get to work, what to wear on the job, who to talk to about issues).
- Conduct themselves in a professional manner.
- Do the agreed upon amount of work.
- Access and use employee benefits (insurance, leave time, raises, etc.), when offered.
- Ask for help getting reasonable job accommodations, when needed.
- Take part in trainings and orientations, and other professional development activities.
- Ask for help if needed to do their job better, seek a promotion, or to restructure their work.



EQUAL EMPLOYMENT OPPORTUNITY

1. What agency policies and expectations exist to support people to exercise rights related to employment?

2. How are staff actively supporting people in this area?

3. Three ways we could improve our policies and supports in this area:

ACCESS TO HEALTHCARE

The Universal Declaration of Human Rights (1948; Article 25) states that “Everyone has the right to a standard of living adequate for the health and well-being of himself and of his family, including food, clothing, housing and medical care and necessary social services.” In addition to stating that everyone is entitled to quality healthcare, the Office of the United Nations (UN) High Commissioner for Human Rights and World Health Organization (2008) also states “the right to health is a fundamental part of our human rights and of our understanding of a life in dignity.” While the UN Declaration of Human Rights applies to everyone, in the United States, despite adopting the UN’s international standards, we do not specifically have rights to health care like many other countries.

Many people with disabilities access healthcare through federal Medicaid, particularly the Home and Community Based Services (HCBS) program.

When it comes to healthcare, agencies should support people to:

- Keep their health information private and confidential.
- Choose their doctors and other health care providers.
- Learn about their medications, diagnosis, and treatment options (including non-traditional, etc.).
- Refuse medical treatments, medications, and interventions if they choose.
- Be involved in their healthcare management: records, appointments, medications, research, etc.
- Meet and talk privately with their doctors.
- Learn healthy habits such as good nutrition and regular exercise.
- Know the health outcomes of not following doctor’s orders or medical treatments.

As a supporter of people with disabilities, you can help by:

- Learning about the person you support’s health care needs and concerns.
- Supporting people to self-manage their healthcare.
- Teaching people about their medications and side effects.
- Supporting people to choose their healthcare providers.
- Assisting people to get to health care appointments.
- Keeping confidential health records secure.

People with disabilities should:

- Learn about health and wellness (e.g. healthy eating, exercise).
- Ask for help if they do not feel well.
- Choose their doctors and other health providers.
- Meet with their doctors and talk directly with them (instead of having their DSP or other person talk to the doctor for them unless they want support).
- Learn about any medicines they take.





ACCESS TO HEALTHCARE

1. What agency policies and expectations exist support people to exercise rights related to healthcare?

2. How are staff actively supporting people in this area?

3. Three ways we could improve our policies and supports in this area:

LEISURE AND REST

The United States Declaration of Independence states that all men are guaranteed the right to “Life, Liberty, and the pursuit of Happiness.” The document states these are “unalienable rights” which governments were created to protect. Also, the Universal Declaration of Human Rights (Article 24) states “everyone has the right to rest and leisure, including reasonable limitation of working hours and periodic holidays with pay.” Leisure is not the same as doing nothing. In fact, rest and leisure can provide health benefits and extend life...”. The United States Constitution similarly says that people have the right to the “pursuit of happiness.”

When it comes to leisure and rest, agencies should support people to:

- Take time off to rest and relax.
- Access the community.
- Set their own daily schedule and routine.
- Have holidays and vacations.

As a supporter of people with disabilities, you can help by:

- Helping people to try new hobbies, interests, or activities.
- Assisting people to access the community (e.g., provide transportation or educate people on using public transportation, if available).
- Providing support with budgeting, planning, and getting ready for trips and vacations.

People with disabilities should:

- Rest and take time for themselves.
- Learn how to relax.
- Explore what activities they enjoy during their “down time.”





LEISURE AND REST

1. What agency policies and expectations exist to support people to exercise rights related to leisure and rest?

2. How are staff actively supporting people in this area?

3. Three ways we could improve our policies and supports in this area:

RIGHTS GUARANTEED UNDER THE HCBS SETTINGS RULE

In January of 2014, The Centers for Medicare & Medicaid Services (CMS) released a new rule for Home and Community Based Services (HCBS) Settings, and people receiving supports through HCBS waivers. The rule (sometimes called the Final Rule, the Settings Rule, or the Final Settings Rule) set requirements for how Medicaid HCBS services had to be provided to ensure people had full access to the community. The rule focused on issues such as choice, autonomy, and individual rights.

The HCBS Settings Rule requires that all home and community-based settings meet certain conditions. People receiving Medicaid HCBS services and supports are entitled to some specific rights, including:

- Choice of where they live (from options including non-disability settings) and who they live with.
- Choice of services and who provides them.
- Privacy, dignity and respect, and freedom from coercion and restraint.
- Autonomy and independence in making life choices.

If a person lives in a provider owned or controlled HCBS residential setting, they have the:

- Right to have visitors at any time.
- Right to access food at any time.
- Right to access the community.
- Right to have a lease or other legally enforceable agreement providing similar protections.
- Right to privacy in their unit including doors that lock and choice of roommates.
- Right to furnish or decorate the unit (home and room).
- Right to control their own schedule.
- Right to a physically accessible setting.

To learn more about the HCBS Settings Rule, visit:

- <https://hcbadvocacy.org/>
- <https://autisticadvocacy.org/policy/toolkits/hcbsrule/>
- <https://www.c-q-l.org/resources/projects/the-hcbs-act-project/>
- <https://www.medicaid.gov/medicaid/home-community-based-services/home-community-based-services-training-series/index.html>
- <https://www.dhs.wisconsin.gov/hcbs/faq.htm#:~:text=The%20purpose%20of%20the%20HCBS,in%20the%20most%20integrated%20setting.>

RESOURCES AND REFERENCES

STATE OF WISCONSIN RESOURCES

- Aging and Disability Resource Centers <https://www.dhs.wisconsin.gov/adrc/index.htm>
- Department of Health Services Family Care: <https://www.dhs.wisconsin.gov/familycare/index.htm>
- Department of Health Services IRIS Program: <https://www.dhs.wisconsin.gov/iris/index.htm>
- Department of Health Services Employment Initiatives Section:
www.dhs.wisconsin.gov/clts/waiver/transition/youcanwork.htm
- Disability Rights WI: telephone number- **1.800.928.8778**
- Statewide Transition Information: www.witig.org
- The Self-Determination Channel: https://www.youtube.com/channel/UCgSBRbXjC_loiTS92fjGvxA
- Wisconsin Board for People with Developmental Disabilities: www.wi-bpdd.org
- Wisconsin Board for People with Developmental Disabilities YouTube Channel:
<https://www.youtube.com/channel/UCSDesdHmoVukAvYurMGRMFQ>
- WI BPDD Wisconsin Living Well's COVID-19 Toolkit: <https://wibpdd.org/index.php/living-well/>
- Wisconsin BPDD Living Well team: <https://wi-bpdd.org/index.php/living-well/>
- You Can Work brochure: www.dhs.wisconsin.gov/publications/P0/p00516.pdf

Other Resources

- Autistic Self Advocacy Network: <https://autisticadvocacy.org/>
- A Guide to Disabilities Rights Laws: <https://www.ada.gov/cguide.htm>
- Citizenship Right Training Manual by Michaela Bishop and Paul Rowe, Oklahoma Department of Human Services
- From Inquiry to Insight: Guided Discussion for Preventing Abuse and Neglect of Persons with Cognitive Disabilities published by Art Dykstra and Amy Tambor
- Green Mountain Self Advocates: <http://www.gmsavt.org/>
- Human Rights Committees: From Compliance to Cultural Commitment by Steve Baker and Amy Tabor, 2016
- Miranda: Rights of Silence: <http://usgovinfo.about.com/library/weekly/aa012300a.htm>
- National Resource Center for Supported Decision-Making: www.supporteddecisionmaking.org
- Self-Advocacy Online: <http://www.selfadvocacyonline.org/>
- Self-Advocacy Resource and Technical Assistance Center: <http://www.selfadvocacyinfo.org/>
- Self-Advocates Becoming Empowered: www.govoter.org
- Self-Advocates Becoming Empowered: www.sabeusa.org
- The ADA: Your Employment Rights as an Individual with a Disability:
<https://www.eeoc.gov/laws/guidance/your-employment-rights-individual-disability>
- The Council on Quality and Leadership's Rights Conversation Cards:
<https://www.c-q-l.org/resources/rights-conversation-cards/>

- The Council on Quality and Leadership's webinar What Rights are Most Important?
<https://www.c-q-l.org/resources/webinars/best-practice-what-rights-are-most-important/>
- The Council on Quality and Leadership's Guide to Employment:
<https://www.c-q-l.org/resources/newsletters/lets-get-to-work-on-employment/>
- The Self Advocacy Alliance of Illinois: <http://selfadvocacyalliance.org/>
- The Social Security Red Book: <https://www.ssa.gov/redbook/eng/resources-supports.htm>
- The Quality Trust: <https://www.dcqualitytrust.org/>
- United Nations Human Rights Convention: http://abilitymagazine.com/United_Nations.html





