

LIVING WELL

Healthy, Safe and Connected



Let's Talk About Rights: A Guide for Families and Guardians



WISCONSIN BOARD FOR PEOPLE
WITH DEVELOPMENTAL DISABILITIES

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LET'S TALK ABOUT RIGHTS

WI BPDD Rights Toolkit to: A Guide for Families and Guardians

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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 This may be due to discrimination, low expectations, and even laws, both current and outdated laws, that may limit the rights of people with disabilities.

This toolkit provides comprehensive information about rights of people with disabilities that are protected by state, federal, and international laws, the US constitution, and various court decisions. These protections help family members and guardians to understand, advocate for, and support people to exercise their personal rights and freedoms. We talk about what the right means, the laws, rulings, etc. that grant these rights, and why these rights are important.

When people understand and use their rights, they have better and safer lives. As a family member or guardian, you have a choice. You can help empower the person and act on behalf of their preferences and dreams to reach their full potential or you can use your authority in ways that puts unnecessary limitations on the person, which inhibits their potential.

As a family member or guardian, you are often the first person who helps the person in your life think about what they want for their future. Often as parents and guardians, you may want to protect them from being hurt or taken advantage. This can often end up not allowing the person to learn about their rights and how to make good choices. This guide will help you learn more about the rights for the person in your life and think about how to have conversations about rights and talk about ways to support the person.

“ We wanted our son to have the chance to grow and learn to make decisions that affect his life. As his parents, we won’t always be around to guide him, and we didn’t want to restrict his life and future happiness. So, we chose not to pursue guardianship and instead to develop a circle of supporters to help him make those big decisions in life.”

-Parent



¹National Council on Disability

RIGHTS GUARANTEED UNDER THE HOME AND COMMUNITY BASED SERVICES SETTINGS RULE

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

The Home and Community Based Services Settings Rule requires that all home and community-based settings meet certain conditions. People receiving Medicaid Home and Community Based 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 Home and Community Based Services 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.



ALTERNATIVES TO GUARDIANSHIP- SUPPORTED DECISION MAKING

Guardianship is sometimes seen as the only way to keep people with Intellectual and Developmental Disabilities safe. However, alternatives to guardianship have emerged, providing a continuum of options that create safety nets while preserving individual rights. These alternatives can be free or also at a much lower cost for families. Even when guardianship is in place, it is the responsibility of the guardian to understand the person's preferences and needs. Autonomy and the ability to make life decisions, both big and small, is fundamental to happiness. "People with disabilities both desire and deserve choices when seeking assistance with daily living that maintains their self-determination and maximum dignity and independence."¹

A new alternative to guardianship, called Supported Decision-Making, has emerged over the last decade. Wisconsin is among several states with a Supported Decision-Making law. Supported Decision-Making is a set of strategies that help people with disabilities have more control over their life and future. Being able to make choices about your life is crucial for the independence and happiness of all people, including those with disabilities. Decision-making is a skill, and everyone needs practice. Just like all of us, people with disabilities continue to grow and gain experience throughout their lives. Regularly involving young people with disabilities in decision-making results in adults who can make informed decisions and direct their own lives.

Supported Decision-Making recognizes a person's abilities as well as their limitations. With Supported Decision-Making, people with disabilities get help from trusted family members, friends, and professionals to understand the situations and choices they face, so they can make their own decisions. Supported Decision-Making enables people with disabilities to ask for support where and when they need it. In addition to a Supported Decision-Making agreement, people may also use Powers of Attorney, Representative Payees, and simple release of information forms to allow families to provide the needed supports and safeguards without going to court and imposing guardianship restrictions.

The person chooses who they trust to help them understand complex information and make informed decisions about their medical, legal, financial, and other life matters. When entering into a Supported Decision-Making agreement, those who can provide help in making decisions are called Supporters. Supporters agree to help explain information, answer questions, weigh options, and let others know about decisions that are made. They do not make the decisions.

Wisconsin Law formally recognizes Supported Decision-Making agreements as legal arrangements that allow people to retain their rights to make their own decisions, while also choosing trusted people (called Supporters) to help them gather and understand information, compare options, and communicate their decisions to others.

Did you know that being able to make your own decisions leads to a higher quality of life? Studies show that people with disabilities who have more control of their lives and are more self-determined are:

- Healthier
- More independent
- More likely to be employed at a higher-paying job
- Better able to avoid and resist abuse

When people with disabilities are less able to make their own choices, they are more likely to feel helpless, hopeless, passive, and are at greater risk of abuse.

People who can use Supported Decision-Making agreements include:

- People with intellectual/developmental disabilities
- People with physical disabilities
- People with mental health conditions
- People of any age with degenerative diseases or conditions that substantially limit one or more major life activities or the ability to provide self-care.

Advantages to a Supported Decision-Making Agreement:

- Can be used for any decisions (e.g., housing, employment, health care, etc.) the person wants support.
- Can be set up for FREE, and without going to court. The law includes certain elements that must be included in the agreement.
- Can be easily updated, changed, or ended by the person.
- A person may have multiple agreements-- or identify more than one Supporter for certain kinds of decisions.
- They are a legally recognized way to let teachers, doctors, bankers, and other professionals know that a person has given a Supporter consent to hear, receive, and communicate information with them.

To learn more about alternatives to guardianship visit WI BPDD's Supported Decision Making and Guardianship Alternatives website at <https://wi-bpdd.org/index.php/supporteddecision-making>



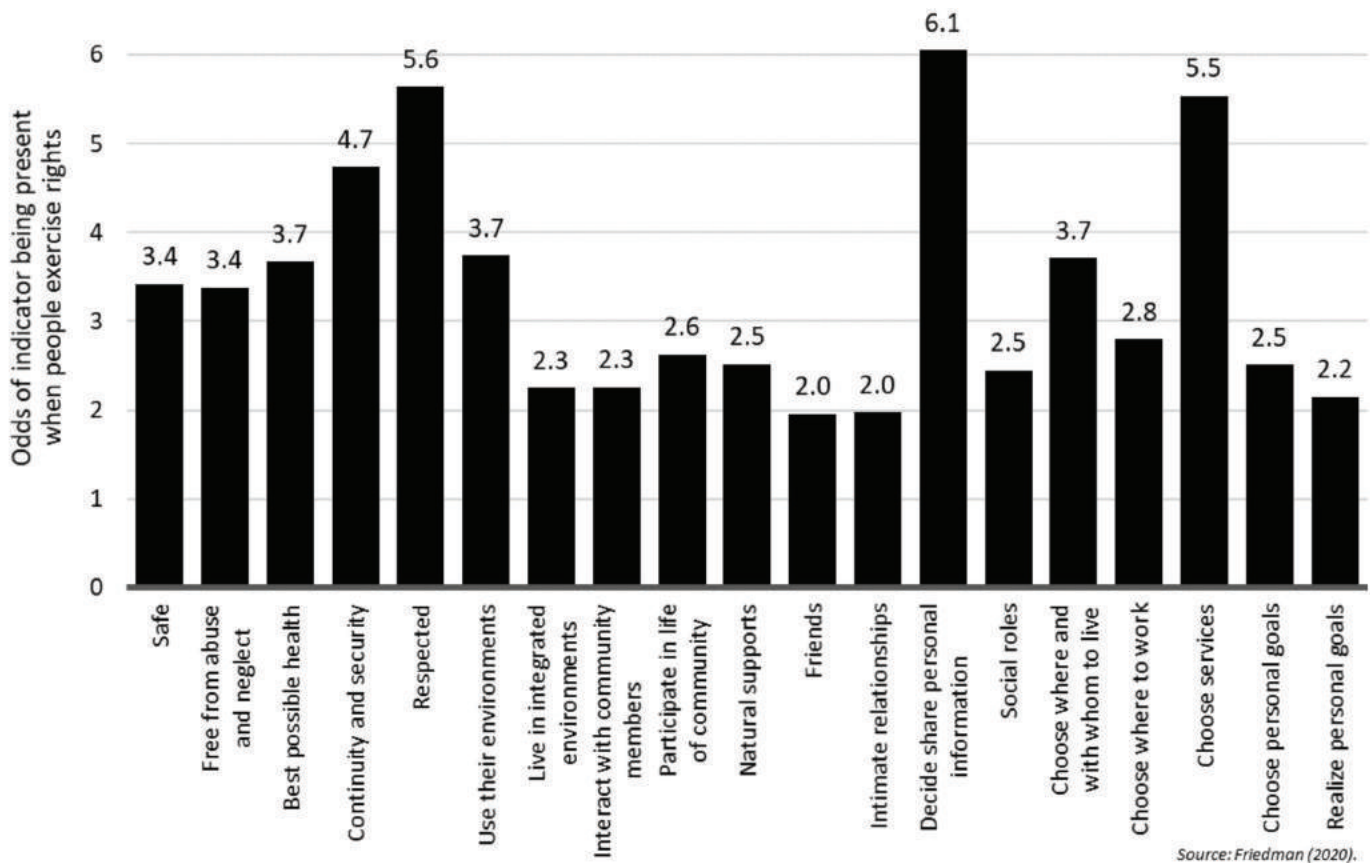
Ginger's Story:

Ginger's foster parents taught her how to make responsible decisions and how to ask for help if needed. At age 18, Ginger's Mom became her representative payee, but not her guardian, to help her manage her Social Security benefits. Her parents have both passed away, but every day Ginger uses the skills they taught her to make decisions at work and at home in her own apartment. She has become a skilled self-advocate, supporting others to make both big and small decisions in their lives. When Ginger needs health care advice, she consults her siblings. For financial questions, she asks her boss, and for social networking and other everyday decisions, she turns to her friends in her local People First chapter.

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.

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.
- Freedom of religious expression.
- 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 services and supports (i.e. Family Care and IRIS) 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.

When people live in provider owned and controlled Home and Community Based Services residential settings, they 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.
- Supporters 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 guardians, family, staff, caregivers, and others can prevent growth and learning.

**Check out the Self-Determination Channel video about the Dignity of Risk:
<https://www.youtube.com/watch?v=dcu3I4QmdMk>**

The principle of dignity and choice is about:

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

Guardians and family members should always presume competence. This means believing people are capable and 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.
- Ask others to help them 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 they choose 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. Wisconsin requires our Family Care and IRIS organizations to protect some rights for people using their services. These agencies are supposed to protect people with disabilities from restrictions or modifications that are put in place. Some states require Human Rights Committees but Wisconsin does not require this as a best practice at this time. If someone you support is being restricted or has limitations on them, you can help them talk with their care manager or IRIS consultant about these issues.

ADDITIONAL DUE PROCESS PROTECTIONS UNDER THE HOME AND COMMUNITY BASED SERVICES SETTINGS RULE

For people getting services and supports through a Medicaid Home and Community Based Service waivers (i.e. Family Care or IRIS) 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 by the provider.

Before the rights of a person receiving Home and Community Based Services can be restricted, the following eight requirements must be met:

1. The restriction or modification must be based 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).
 - Examples of restrictions: Not having access to food, not being able to see your family, not having control of your money.
2. There must be documentation in the person-centered plan that positive interventions have been tried but have not worked.
3. There must be documentation that 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!).
4. There must be 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!)
5. There must be processes in place to measure if the restriction is helping.
6. There must be set time limits for regular reviews to decide if the restriction is still needed, or if it can be stopped.
7. There must be a process to get informed consent (permission) for the restriction from the person.
8. There must be assurances that the limitation/restriction will cause no harm.

When it comes to equal protection and due process, guardians and family members should:

- Help people to understand what a restriction is and 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!
- Support people to attend and speak up at any meeting where the restrictions are discussed.
- Provide support (and enlist the help of others) to people to learn new skills so their rights can be restored.
- Make sure people are not discriminated against based on their disability or other category such as race, age, sexual orientation, or gender identity.
- Learn about Supported Decision Making (a model for people with disabilities to exercise and/or restore rights) and support people in the Supported Decision-Making 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.



PLANNING QUESTIONS ABOUT EQUAL PROTECTION AND DUE PROCESS:

1. What has the person shared with me about their preferences for services and ensuring they receive due process?

2. What more can I do to support the person to understand and exercise their rights about their services and ensuring they receive due process?

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 family members and guardians should:

- Presume competence and believe that people can, with the proper support, control their money.
- Refrain judgement about how people spend their money.
- Support people to learn how to manage their funds (though only to the extent necessary) and do their own banking (in person and online).
- Support people to decide who keeps and holds their money, check book, and bank cards.
- Support people to decide the amount of money they carry.
- Support people to decide how much of their money to put in their bank account and how much to keep out.
- Help people choose a bank that meets their needs and preferences.
- Help people pick safe storage options for any cash or credit cards they keep in their home, if needed.
- Be informed and educated about sources of money like SSI (Supplemental Security Income), SSDI (Social Security Disability Insurance) and other sources like trust funds.
- Review and question 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), and how to responsibly handle benefit income, earned income, and gifted income.
- Learn about budgets and expenses.





PLANNING QUESTIONS ABOUT CONTROL OF MONEY:

1. What has the person shared with me about their preferences for controlling their financial resources?

2. What more can I do to support the person to understand and exercise their rights with financial resources?

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, family members and guardians should:

- Ensure people have access to the phone, internet, film, newspapers, television, social media, etc. and in accessible formats.
- Ensure people are able to express opinions, thoughts, and ideas without fear of "payback" or retaliation.
- Ensure people are able to hold private conversations with people they want.
- Help people to understand they can express themselves without fear of retaliation.
- Listen to what people have to say.
- Ensure people have access to any Alternative and Augmentative Communication (AAC) devices or other communication tools they need (e.g., American Sign Language, picture books, communication devices, voice services, etc.)
- Support people to attend and participate in all meetings (support and service planning, behavior, rights modification, etc.) about themselves.
- Seek out training and support for people to learn how to speak up and advocate for themselves.
- Support 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.





PLANNING QUESTIONS ABOUT FREEDOM OF SPEECH AND EXPRESSION:

1. What has the person shared with me about their preferences for freedom of expression and self-advocacy?

2. What more can I do to support the person to understand and exercise their rights related to freedom of expression and self-advocacy?

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:

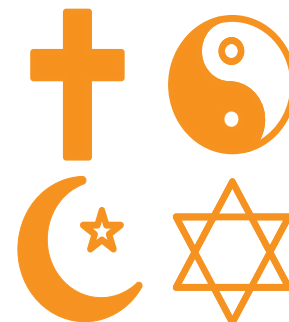
- Express their religious beliefs.
- Practice their religious beliefs by going to religious services, praying, wearing clothes that show their beliefs.
- Receive and participate in faith-based rituals (e.g., sacraments, Shabbat, Sawm-fasting, etc.) if desired.
- Become a formal member of a religious 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, family members and guardians should:

- Learn about different religious and spiritual options and opportunities.
- Ensure supports and transportation are available to assist people to participate in religious and spiritual activities and practices.
- Assist people to attend services of their choice (i.e., not just a service that is convenient for staff or the home).
- Respect that other people's beliefs may differ from your own.
- Make sure people are not coerced or manipulated in the name of religion.

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.





PLANNING QUESTIONS ABOUT FAITH BELIEFS:

1. What has the person shared with me about their preferences religious expression?

2. What more can I do to support the person to understand and exercise their rights related to religious expression?

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, family members and guardians should:

- Restore people's right to vote if this right has been restricted.
- Support people to learn about registering to vote: <https://disabilityvote.org/>.
- Help people find unbiased information about people running for office, including ones that align with people's own belief systems (<https://www.isidewith.com/>).
- Provide or find support for people to cast their vote.
- Help people get to the polling site, or support them to fill out an absentee ballot, when needed.
- Make 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.





PLANNING QUESTIONS ABOUT VOTING RIGHTS:

1. What has the person shared with me about their preferences about voting?

2. What more can I do to support the person to understand and exercise their voting rights?

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 Home and Community Based Services Settings Rule which ensures individual rights of privacy (and dignity and respect) for people receiving Home and Community Based Services services. The settings rule states that people receiving Home and Community Based 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 doors. 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 10).

When it comes to privacy, family members and guardians should:

- Support people to keep their information private and confidential.
- Help the person know what information you keep about them, where it is stored, and who has access to it.
- Ensure that people have access to private spaces and support if needed for hygiene and other personal care tasks.
- Ensure that people have keys to their home and locks on their doors.
- Help to maintain the confidentiality of records, including financial records, that you have access to.
- Only release private information with informed, written consent and for a specific time and purpose.
- Ensure that you keep personal information secure and not posted in public places.
- Seek out training and support for people to learn 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).

PLANNING QUESTIONS ABOUT RIGHT TO PRIVACY:

1. What has the person shared with me about their preferences about their privacy?

2. What more can I do to support the person to understand and exercise their rights related to privacy?

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 Home and Community Based Services 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 Home and Community Based Services services).
- Establish and maintain friendships.

When it comes to freedom of association, family members and guardians should:

- Make sure the person can spend time with friends and family where and when they want.
- Ensure they have access to telephones and computers to connect with friends and family.
- Ensure agencies do not include restrictions on freedoms to associate (volunteers, visiting policies, etc.).
- 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 based upon both people engaging in the relationship.
- Respect other's beliefs and opinions, even when they are different from their own.
- Take responsibility for their words and actions.
- Explore new activities and groups.



PLANNING QUESTIONS ABOUT FREEDOM OF ASSOCIATION:

1. What has the person shared with me about their preferences about who they associate with?

2. What more can I do to support the person to understand and exercise their rights related to the freedom to associate?

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:

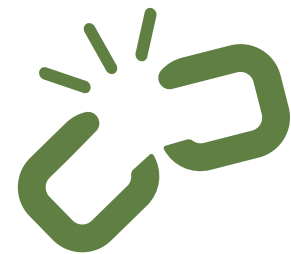
- Not be bullied, mistreated, or ignored.
- Feel safe in their own home (e.g., people should not be intimidated or hurt by housemates or staff; property should be safe from theft).
- Be free from abuse, neglect, mistreatment, and exploitation (ANME).
- Not be restrained and if restraint is used, due process is required (see page 10 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, family members and guardians should:

- Teach people about their rights.
- Learn about agency policies and procedures around abuse, neglect, mistreatment, and exploitation (i.e., what they are, clearly state they will not be allowed).
- Ensure people understand what ANME is and what to do if they (or someone they know) is a victim of ANME.
- Choose to work with agencies that train staff on ANME prevention, detection, and reporting.
- Support people if they become a victim of ANME by listening to them and connecting them with supportive resources and services, such as the Victim’s Advocacy Resource Center <https://disabilityrightswi.org/resource-center/victim-advocacy/>
- Treat people with dignity and respect. Do not dismiss their trauma.

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.





PLANNING QUESTIONS ABOUT FREEDOM FROM HARM AND CRUEL AND UNUSUAL PUNISHMENT:

1. What has the person shared with me about their experiences and understanding about ANME?

2. What more can I do to support the person to understand, are protected from and know how to respond to ANME?

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 ownership and possessions, family members and guardians should:

- Support people to learn to manage their own money and purchase things (possessions).
- Connect them to support and resources to learn financial literacy skills.
- Respect their decisions on what to buy and own, and not judging them on their decisions.
- Ensure people can freely access their personal items, including food and clothing.
- Ensure people can shop for, and safely store, their property, as desired.
- Ensure people have proper clothing for different temperatures, activities, age group, and cultural norms.
- Ensure people can access their personal belongings without asking permission (e.g., property, clothes, hygiene supplies, food, etc.).
- Support people to decide who borrows or uses their things.
- Help people get protection or insurance for personal belongings, such as renters insurance.
- Support people to learn about and understand laws about leasing, renting, or buying property and the pros and cons of each option.
- Ensure any lease and tenant rights include protections from unlawful eviction and discrimination, when renting a home or living in a provider operated Home and Community Based Services setting.
- Ensuring 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.





PLANNING QUESTIONS ABOUT RIGHT TO POSSESSIONS:

1. What has the person shared with me about their possessions and the things they want to own?

2. What more can I do to support the person to understand and exercise their rights related ownership and possessions?

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, family members and guardians should:

- Help people acquire any technology (such as communication devices, software, and smart technology) that will support them in their education.
- Support people to request and receive reasonable accommodations they need to learn and succeed.
- Support people to only answer essential questions about their disability to request accommodations.
- Encourage people to lead their Individualized Education Plan meetings, or Section 504 meetings.
- Promote continued education (for example, General Education Diploma (GED), continuing education, or certifications, etc.) and lifelong learning.
- Support people to use school buses and public transportation to attend classes.
- Working with people and schools to find tutors or mentors, if needed.
- Teach people about local social and community services, such as the local library or civic groups.
- Recognize that many tests and assessments are culturally and/or racially biased and advocate that inappropriate testing and assessments should not be used to discriminate against people or limit their opportunities.

People with disabilities should:

- Learn about disclosure requirements for obtaining services.
- Learn about their rights under IDEA and the American's with Disabilities Act (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.





PLANNING QUESTIONS ABOUT EQUAL EDUCATION

OPPORTUNITY:

1. What has the person shared with me about their preferences for learning and education?

2. What more can I do to support the person to understand and exercise their rights related to learning and education?

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. In 2014, the US Congress passed landmark legislation called the Workforce Innovation and Opportunity Act (WIOA) to expand employment, education, training and support services for youth and adults with disabilities.

When it comes to employment, family members and guardians should:

- Ensure people are provided the opportunity to seek competitive employment.
- Ensure people can choose where they work.
- Ensure people earn at least federal or state minimum wage and support people to advocate for competitive wages and raises.
- Support people to engage in career exploration to expose them to a variety of jobs so they can make informed choices about work.
- Let people know they have a choice about their services and supports and who provides them.
- Support people to engage in their job search, including finding opportunities, completing applications and preparing for interviews.
- Seek out an employment coach or mentor, if needed.
- Help people request reasonable accommodations (e.g., improved accessibility in the office, flexible hours, reserved parking, assistive technologies, job restructuring, personal assistance).
- Support people to retire when they reach typical retirement age.
- Assist people to keep their employment (e.g., ensure their access to transportation or teach them to use public transportation, if available).

People with disabilities should:

- Explore job and career options to find out what interests them.
- 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 a different job, or to restructure their work.





PLANNING QUESTIONS ABOUT EQUAL EMPLOYMENT OPPORTUNITY:

1. What has the person shared with me about their employment preferences?

2. What more can I do to support the person to understand and exercise their rights related to employment and achieve their employment goals?

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, family members and guardians should:

- Understand the person’s healthcare needs and preferences.
- Help people keep their health information private and confidential.
- Support people to self-manage their healthcare to the greatest extent possible, including
 - choosing their own doctors and other health care providers,
 - understanding their own medications, diagnosis, and treatment options (including non-traditional, etc.), and
 - understanding the health outcomes of not following doctor’s orders or medical treatments.
- Ensure people have the right to refuse medical treatments, medications, and interventions if they choose.
- Ensure they can meet and talk privately with their doctors.
- Teach and/or seek out supports for healthy habits such as good nutrition and regular exercise.

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.





PLANNING QUESTIONS ABOUT HEALTH CARE:

1. What has the person shared with me about their preferences related to their health and healthcare?

2. What more can I do to support the person to understand and exercise their rights related to health and healthcare access?

LEISURE AND REST

The United States Declaration of Independence states that all people 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, family members and guardians should support people to:

- Take time off to rest and relax.
- Access the community (e.g., provide transportation or educate people on using public transportation, if available).
- Set their own daily schedule and routine.
- Help people to try new hobbies, interests, or activities.
- Provide 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.”





PLANNING QUESTIONS ABOUT LEISURE AND REST:

1. What has the person shared with me about their preferences for rest and leisure activities?

2. What more can I do to support the person to understand and exercise their rights related to leisure and rest?

RESOURCES AND REFERENCES

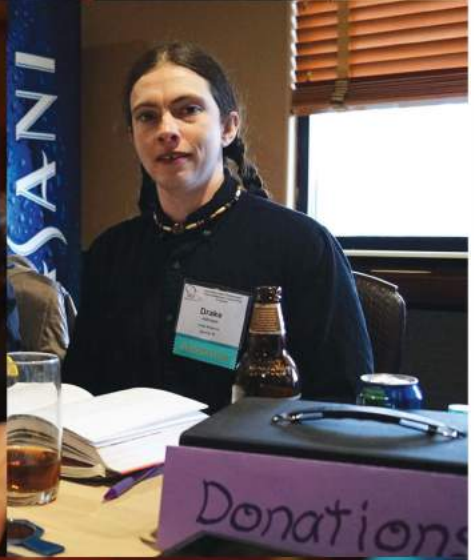
STATE OF WISCONSIN RESOURCES

- 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**; website- <https://disabilityrightswi.org/>
- People First Wisconsin: telephone number- **1.414.483.2546**; website- <http://www.peoplefirstwisconsin.org/>
- 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/>
- Green Mountain Self Advocates: <http://www.gmsavt.org/>
- 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.sabeusa.org
- Turning Rights Into Reality: How Guardianship and Alternatives Impact the Autonomy of People with Intellectual and Developmental Disabilities
https://ncd.gov/sites/default/files/NCD_Turning-Rights-into-Reality_508_0.pdf
- Home and Community Based Services Advocacy Coalition: <https://hcsadvocacy.org/>

¹ National Council on Disability, The State of 21st Century Long-Term Services and Supports: Financing and Systems Reform for Americans with Disabilities, December 2005, accessed February 11, 2019, www.ncd.gov/publications/2005/12152005



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