

Informed Consent for Rights Modification

Name: _____

0. Before you begin (for providers and case managers)

Don't start by simply filling out this form. Is a Rights Modification really necessary, and if so, must it look exactly as you initially envisioned it? Be creative in thinking about alternative approaches! What else might work with this individual? What has worked with others in similar situations in the past? Have you discussed with the individual what their preferences and needs are? Have you afforded them the opportunity to work with people of their choosing (including advocates, peers, people who help them with supported decision-making, friends, and family) who can help them evaluate the pros and cons of your proposal and the alternatives? Try to negotiate a solution that works for everyone while avoiding, or at least minimizing, any impact on people's ability to fully exercise and enjoy all of their rights.

If you still feel that you must proceed to a Rights Modification, this form should reflect that you had a robust conversation and thought process leading you to that point. The process is much more than simply filling out this form: the form just summarizes information showing that the overall process was thorough and appropriate.

In this situation, providers may fill in information relating to items 1 through 6, reflecting their conversations and history with the individual, before giving the form to the case manager. The case manager must carefully review the information provided and discuss it with the individual (and their guardian/other legally authorized representative, if applicable), making sure that it fully explains what the individual needs to know to make an informed decision. In the course of this discussion, the individual and the case manager may modify the information on the form. They may also initiate their own form at any time. After they have finished modifying/completing the form, they should sign at the bottom. Only the case manager may obtain these signatures.

Additional guidance for completing the form:

- This document should clearly, thoroughly, and respectfully explain all elements for the individual, so they can make an informed decision about signing.*
- Use plain language, addressed directly to the individual, as this is a document for their review and consideration.*
- As a part of ensuring plain language, there is generally no need to cite statutes or regulations or to use legal terms of art. This information certainly can be given by the provider or case manager, if the individual or guardian would like these references.*

1. Description of your proposed Rights Modification

Specify what right will be modified and how it will be modified, to be sure the individual understands what to expect. (For example, "your right to come and go will be modified in that staff will always accompany you when leaving your home, except when you are at work or with your family," or "your right to privacy will be modified in you will not lock your bedroom door, in case staff need to come in to help you during a seizure.") Be sure to

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address only one Rights Modification per form. This helps you to complete the narrative clearly and in turn, ensure that the individual understands each right that is affected and each modification being proposed.

2. The reason for your Rights Modification, based on your assessed needs

Explain what data, behavioral concerns, or other information has led to the proposed Rights Modification. The reason must be based on the individual's needs and protecting their or someone else's health, safety, or wellbeing, and not simply a request from someone in the individual's life, including family or a guardian; the convenience of the provider; or historic issues that may no longer be problematic. (For example, "you have sexual behavior issues and have used the internet to interact inappropriately with strangers this past month," or "you have Prader-Willi Syndrome and with free access to food, you have been eating to the point of becoming sick.") The proposed Rights Modification described in Item #1 must be proportionate to the assessed need, meaning that it is no more restrictive than needed to protect the identified health/safety/wellbeing interests of the individual or others.

3. Other ways you have been supported that have not worked on their own

Carefully detail what positive interventions and supports and what less-intrusive approaches have been implemented, without the result needed. (Examples include "you have been attending therapy weekly," and "you have tried to practice self-monitoring techniques for making healthy food choices.")

4. These are things you can do to have your rights restored, and how your service provider will support you and track how you're doing

Explain what positive behaviors and objective results the individual can work toward to demonstrate that the Rights Modification is no longer needed, with interim steps to have part of their rights restored. Specify who will collect and review this information, and on what schedule. Specify how the individual will be supported to achieve these behaviors/results. (For example, "you will attend therapy every week, staff will help you use your safety plan by reminding you about it as needed, and you will be able to use the internet with staff supervision; then, if you demonstrate responsibility for three months (meaning that staff observe that you do not try to hurt/harass others online), you will have five-minute periods on the internet without supervision; then, if you continue to demonstrate responsibility each month, these periods will get longer by 5 minutes per month"; or "you will get to choose some foods to always have available and staff will suggest and help support you to not eat it all at once, and as that improves (meaning that staff observe you are able to stop eating those foods after 1-2 portions in a sitting), more choices will be available.")

5. This is how the Rights Modification will affect your daily life, and how your staff will support you to avoid harm and discomfort because of the modification

Detail how staff will mitigate potential harm or discomfort so that they can assure that the modification will cause no harm to the individual. (For example, "although you are not able to come and go on your own, you will still be able to choose community activities you enjoy and staff will make sure you can do these things"; "although you are not able to safely lock your bedroom door, you will still have privacy by being able to close your door without

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locking it, by having staff always knock and wait for permission to enter except when they believe you are having a seizure, and by having a separate way to lock up important belongings to keep them safe”; “since you will not be allowed to watch some types of shows or movies on TV, you will get to choose from other appropriate options.”)

6. You do not have to consent to this proposed Rights Modification. Here are some other options.

Explain alternatives that are available, along with their most significant likely consequences (pros and cons). (For example, “if you do not agree to this restriction on your access to food, you can eat whatever you want, and you may experience uncontrolled weight gain, which has made you uncomfortable in the past, and which could create the following health risks,” or “if you do not agree to this restriction on your access to the internet, you can do whatever you like online, and you risk engaging in misconduct that could hurt other people and get you in trouble with the law.”) If relevant, note that the provider might seek to terminate services for the individual, and that the individual may arrange to receive services from a different provider/at a different setting, and/or to receive more or different services and supports. The case manager must help the individual understand these options.

Before making a decision, please know:

- You have the right to get all of your questions and concerns answered. You can talk to advocates, peers, people who help you with supported decision-making, friends, family, and others. Feel free to have these conversations on your own or to ask your staff or your case manager to help set up these conversations.
- You should talk to your case manager to be sure you understand the proposed Rights Modification and the other information in this form. You can include anyone you want in these conversations.
- You can write on and alter this form to be sure you agree with it before you sign it.
- If you agree to this Rights Modification, you will review that decision and the information supporting it with your case manager, and others of your choosing, at least every year. This review can be sooner if you or others would like to consider changes at any time.
- If you agree now but change your mind later, you have the right to withdraw your consent.

If you agree with this Rights Modification, please sign below.

Individual signature

Date

Guardian/other authorized legal representative signature (if applicable)

Date

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Case Manager signature

Date

The case manager enters a summary of the finalized information from this form, with any modifications from the individual and/or case manager, into the case management system and keeps a copy of the signed form, along with any discussion notes, on file. The case manager distributes copies of the case management system summary and the signed form to providers involved in implementing the Rights Modification.

Provider agencies do not sign this form. Provider requirements for staff with regard to training, protocols, or other plans for implementation, are handled separately. Upon receiving a copy of the signed form and the summary from the case management system, provider agencies can attach it to their other documentation, including staff signing off to indicate they reviewed and understand what the individual has agreed to.

{Confirm alignment with BUS/Aerial fields}