

GUIDANCE FOR COMPLETING THE RIGHTS RESTRICTION INFORMED CONSENT RESPONSE SHEET

Rights restriction

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This guidance document is to be used by the support team. It is to help them fill out the optional Rights Restriction Informed Consent Response Sheet for the person. The expectations for each step in the sheet are outlined below.

Before you begin reviewing this document for the Rights Restriction Informed Consent Response Sheet:

- Ensure the support team has exhausted all non-restrictive options before initiating or continuing a rights restriction. Always consider what else might work for this person. Consider less prohibitive restrictions even if they were considered in the past. Ask the person if they have ideas as to what else the team can try.
- Make a plan to present the rights restriction to the person in a way that will make sense to them. If a verbal conversation is difficult, work with the support team to determine what informed consent could look like for the person. (Note that no response does not mean consent, unless that is how the person would communicate agreement.) We recommend using the same communication strategies that have been identified in the PCSP to work toward informed consent.

Guidance for completing the Rights Restriction Informed Consent Response Sheet:

- Beginning with Step 1, this guidance document should help the support team clearly, thoroughly, and respectfully explain all required elements of a rights restriction for the person, so they can make an informed decision about their consent to a restriction of their human rights.
- The team member(s) completing and reviewing the Rights Restriction Informed Consent Response Sheet with the person should use plain language, addressed directly to the person. The response sheet is to document the person's review and consent. It is for them to keep.
- As a part of ensuring plain language, there is generally no need to cite statutes or regulations or to use legal terms. This information can be provided by the provider or support coordinator if the person or guardian would like these references.
- Informed consent meetings and discussions should always include the person and their guardian (if applicable).
- Give the person the opportunity to review the response sheet with people of their choice to help them evaluate the pros and cons of the proposal for the rights restriction. These people may include their support coordinator, provider staff, a DSPD representative, independent advocate, peer, people who help them with supported decision-making, friends, or family.
- The support team should have had a robust conversation and thought process leading to the decision to implement a rights restriction. The summarized information in the response sheet should show that the overall process was thorough and appropriate.

Step 1: Explain why the person needs a rights restriction. Include the reason for the restriction based on the assessed need they have.

Review the rights restriction documentation. This should include the positive interventions and less intrusive methods used. It can include historical data provided by family members or support coordinators. Include a description of how these interventions and methods have been received to help the person understand why there is a proposed restriction at this time.

Step 2: Explain how the person can get the restriction removed. How will staff support the person? How will progress be tracked?

Guidance: *Explain what progress and success will look like. Explain the positive behaviors and objective results the person can work toward to show that the rights restriction is no longer needed. Include any intermediate steps that could lead to part of their rights being restored. Specify who will collect and review this information, how that information will be communicated to the person, and on what schedule. Explain how the person will be supported to achieve these results. (For example, “we will help get you to therapy every week,” “staff will help you use your safety plan by reminding you about it as needed,” and “we will supervise your use of the internet.” “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. If you continue to demonstrate responsibility, these periods will get longer by 5 minutes.”)*

Step 3: Describe how the restriction will affect the person’s daily life. How will their staff help them avoid harm and discomfort from the restriction?

Guidance: *Detail how staff will lessen any potential harm or discomfort so that they can assure that the restriction will cause no harm to the person. The Provider Human Rights Committee report should also give assurances that the restriction will not cause harm.*

Describe how the restriction can benefit the person. For example, “although you are not able to lock your bedroom door, you will still have privacy by being able to close your door without 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.”

Step 4: Explain what giving consent for this rights restriction means. What could happen if the person agrees to the restriction? What could happen if the person doesn't agree to the restriction?

Guidance: Explain alternatives that are available, along with their most significant likely consequences. Content for the discussion must include explanations of alternatives, the right to refuse the restriction and any natural consequences, what additional informed decision-making support is available, the role of the guardian in making or approving the rights restriction decision (if applicable), and any other subject important to and for the person. This document, *Rights Restrictions for Providers*, might be helpful in preparing for this part of the discussion.

(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 could create the following health risks, etc." or "if you do not agree to this restriction of your access to the internet, you can do whatever you like online, and then 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 person, and that the person may ask to receive services from a different provider or support coordinator, at a different setting, and/or to receive more or different services and supports. Not consenting to the rights restriction could mean an increased risk for incarceration or institutionalization.

Step 5: Review these statements with the person before they make a decision:

- I can make changes if I want. My support team can help me.
- I can ask questions about this form and get help from people I trust to make a decision. My support coordinator can help me. I can also get help from people at the Division of Services for People with Disabilities (DSPD).
 - The DSPD Constituent Services Team (DSPD@utah.gov or call 801-538-4091)
 - The DSPD Community Inclusion Team (CommunityInclusionTeam@utah.gov, or call 801-538-4200)
- I can review this restriction whenever I want. My support team will review it at least yearly.
- I can let my support coordinator, a trusted staff person, or a family member know if this rights restriction is not being enforced.
- I have a choice in my services and who provides them. If I would like help with choosing your services, I can ask:
 - My support coordinator
 - My provider
 - The DSPD Constituent Services Team (DSPD@utah.gov or call 801-538-4091)
- I know that I can remove my consent for the restriction at any time. (See Remove Informed Consent Form.)

Describe the process for obtaining informed consent of this rights restriction.

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The support team should summarize the process used to obtain informed consent. If the person is non-speaking, describe how the team knows the person gave consent. Ensure that the person knows they can change their mind about the restriction. They can also request help to understand the restriction and what it will mean in their life.

The person and their support team will sign the informed consent response sheet.