

Office of Developmental Disabilities Services

Knowing Your Rights during COVID-19

Background

It is important for people with intellectual and developmental disabilities to know they have the right to the same medical care and treatment options as anyone else. This fact sheet outlines some important information people with I/DD need to know during the COVID-19 pandemic.

You cannot be treated differently because of your disability.

- You cannot be denied medical treatment because you have a disability.
- You can go to a doctor or hospital just like anybody else. If you have COVID-19 symptoms call your doctor and get direction on what to do. Call back if you get worse.
- You have the right to get the treatment you need. If you get COVID-19 and need assistance to breathe, you have the right to access medical equipment like a breathing machine (ventilator).
- You have the right to make an informed choice regarding treatment or care. This includes having information in a format accessible to you. You also have the right to have someone you trust present when discussing treatment options.
- You have the right to document and make sure others know your preferences for medical care if you get sick.
- You have the right to have a person you trust with you for support at the hospital. Hospitals must allow you to identify at least three different people for support.

Before you go to the doctor or a hospital:

- Talk with people you trust if you want their help making decisions. It is a good idea to write down your wishes for medical treatment **before** you get sick. Even though it can be hard to think about, it is important to write down what kind of care you want if you get very sick, and who you want to support you. Hospitals generally have to follow the wishes you document.
- Contact important people in your life to make sure they and your designated supporters know you are sick and are going for treatment. This could include family members, friends, or your case manager.

- You can refuse or agree to any treatment, and you can also change your mind about your treatment options at any time.
- Make sure you have any documents you need including:
 - Any communication materials you may need, such as a communication board, iPad or other tablet.
 - Paperwork you have completed to document your treatment preferences.
 - Emergency contact information for people close to you.
 - A list of any medications you are taking, and anything you are allergic to.
 - Any documents you need about your medical condition.
- Ask your medical providers to make sure a copy of all this information is put in your medical chart and also make sure a trusted person has a copy.

Once you are at the doctor or hospital:

- Make sure your health care team knows your treatment and communication preferences.
- If needed, ask hospital or clinic staff to talk slowly and clearly.
- You can ask the doctor any questions you have or request more information.
- If there are certain things that bother or upset you, let your medical providers know. For example, if you are scared about needles or having your blood taken, tell them so they can find ways to accommodate you.
- When you talk with your medical providers, they should tell you all the different options to treat you while you are sick including any side effects for any choice.
- You have the right to have a person you trust with you for support at the hospital. Hospitals must allow you to identify at least three different people for support.
- Hospitals cannot require or suggest you are required to complete any form that documents a decision to withhold life-sustaining treatment (for example, in an Advance Directive, POLST, etc). Hospitals often ask patients if they want to complete these forms. You do not have to sign anything you do not understand or do not want to sign. You can ask someone you trust for support to gather more information and make a decision.
- A hospital must ensure a support person you have designated is present for a conversation about hospice or about withholding life-sustaining treatment, unless you do not want your support person there.
- If you have to stay overnight in the hospital, make sure your medical providers know they need to let your support team know. Make sure the medical providers communicate with your support team before you leave or are discharged from the hospital, so they can prepare and can help you get any new equipment or medicine needed.