

Future Decisions



Why Should I Plan for Decision-Making in the Future?

Everyone's ability to make decisions changes across a lifetime, including people with intellectual and developmental disabilities (IDD).

- › Young people can learn to make better decisions as they grow up and no longer need someone to make decisions for them. They make small decisions and then bigger decisions as they learn from the good and bad consequences of their choices.
- › As people get older, they may lose the ability to make decisions as well as they used to. People with IDD are at particular risk for dementia and Alzheimer's as they get older. They may need more help from others to make decisions.

People with IDD and their families must plan for these changes, so that decisions can be made, even in a crisis.



SUPPORTED DECISION-MAKING AND FUTURE PLANNING

Unexpected things can happen at any time that affect people's ability to make their own decisions. If plans aren't in place, options can become limited. Take steps before a crisis, when things are calm, to make sure a person's choices are respected.

1 Discuss what types of decisions or changes may need to be made. What types of decisions will people need help with? What type of help do they want? Who do they want to help them?

2 Consider decision-making alternatives. Some alternatives for a person with IDD and their supporters to consider include:

- **Supported decision-making agreements.** A person with IDD makes their own decisions but chooses what types of decisions they want help to make and who they want to help them. [Here is an example around making health care decisions.](#)
- **Limited powers of attorney.** A person with IDD chooses who they want to make decisions for them. The authority is only for a certain decision or only for a certain amount of time.
- **Durable powers of attorney.** These legal documents say who a person wants to make decisions if a time comes when they cannot make their own decisions. These documents put in place a process for what should happen before an emergency or change in decision-making ability occurs.
- **Advance directive for health care decisions.** These legal documents say what life-saving treatment a person wants or does not want to receive. These documents also say who can make health care decisions if the person cannot.

- 3 Decide how decisions will be made and establish a decision-making agreement.** Consider consulting with a lawyer to help create these legal documents. It's important that the [lawyer](#) understands that people with IDD can and should make their own decisions to the best of their ability and know about person-centered decision-making for people with IDD. If your family can't afford a private lawyer, contact the [protection and advocacy program](#) in your state.
- 4 Share plans for decision-making in the future.** Make sure other people who support the person, like friends, family members, staff, or doctors also know how decisions will be made in an emergency. It's important to keep a record of how decisions are and will be made. You can keep this record online in a [Build Your Plan Account](#). You can also keep a paper record of important information for easy access in an emergency by completing a [Letter of Intent](#).
- 5 Review how people want to make decisions regularly.** This may be yearly or more frequently if a person's ability is changing quickly. Make sure the person knows that no matter how decision-making changes, their ideas, thoughts, and wishes will always be respected and considered.
- 6 Provide emotional support when people are no longer able to make decisions that they used to make.** The person whose ability is changing may be scared, angry, or upset. Assure the person that they are still valued, that their opinions matter, and that people will be there to help them.





GUARDIANSHIP AND FUTURE PLANNING

While guardians are authorized by a court to make decisions for a person, they should empower the person they support to make as many decisions for themselves as possible and support them to become more independent in making their own decisions. When a guardian is unavailable to make a decision for any reason, there must be a plan in place for who will make decisions in the guardian's place.

1 Identify 2 – 3 people who can make decisions when the guardian is unavailable. The person with IDD, their trusted family and friends, and other supporters should meet to identify one or more successor guardians—people who could make a decision when the guardian is not available. The team may want to discuss:

- › Who else is trusted to make decisions on behalf of the person with IDD?
- › What types of decisions should be made immediately? What decisions could wait until the guardian is available again?

2 Write down these decisions in this person's plan. Include current contact information and share these decisions with people who will need to know, including other family, case managers, and doctors. Ask the court to identify the successor guardian in court documents. The court can name anyone as a successor guardian. Having a plan for what the person and family would like to occur may help guide the court's decision.

3 Empower people to make daily decisions. Some activities that may help people build their skills include:

- › Encouraging people to make small day-to-day decisions, like what to wear, what to eat, and what to do
- › Discussing the good and bad things that could happen for each choice the person could make
- › Asking a person with IDD about the steps they took to make a decision
- › Helping the person learn from their experiences and mistakes
- › Exploring bigger decisions the person can make, on their own or with support, as they gain more experience
- › Exploring [assistive technology devices](#) that can help build decision-making and communication skills
- › For more steps you can take, check out A National Gateway to Self-Determination's [It's My Future booklet](#) and [iPad application](#).

4 Review ability to make decisions every year. As people's skills grow over time, how decisions are made should change. The guardian, person with IDD, trusted family and friends, and other supporters should seek to identify where a person may be able to make their own decisions, with or without support.

5 Take steps to formally restore rights through court. If a person has a full guardianship but can make some or most decisions by themselves, the guardian, the person, their family, and their supporters should seek to restore rights through the court. This could be to limit guardianship only to decisions that are needed or to fully remove guardianship and use other decision-making tools.

WHAT TO DO: MY GUARDIAN IS NOT LISTENING!

If you believe your guardian is not acting in your interests or you think that you should have your rights restored and no longer have a guardian, contact your [protection and advocacy organization](#).