

Decision-Making: Planning & Supports

People with intellectual disabilities (ID) make decisions about their own lives, every day. In fact, the law assumes that people with ID have this capacity. However, in the same way that many of us look for input from people close to us when we make major decisions, sometimes people with ID need support.

Many supports require no paperwork or legal action – just family or friends who are willing to help. However, some supports require the person or a court to take action.

With planning, a person with ID, family and close friends can find the right level of supports. It's best to plan early, so supports are ready when needed.

Finding the Right Support

Not every decision needs support. Am I hungry? Do I want to watch TV? We all make decisions like this every day. Questions to help you talk about whether a specific decision needs support include:

- ◆ How much risk is involved to life, safety and health?
- ◆ How big is the impact on the person's life?
- ◆ How long would the person have to live with the decision?
- ◆ How hard would it be to undo the decision?
- ◆ Is the decision similar to other decisions the person has experience with? Are there ways to build on the person's past experience to help make the decision?
- ◆ Is the decision likely to be challenged, including by the legal system?
- ◆ What is the least intrusive, most informal level of support that might work?

Sometimes, adults with ID and their loved ones disagree over whether supports are needed. Decisions about major issues like dating, where to live, and money can be difficult as parents and family members struggle with their fears. However, some supports – like guardianship – take away many or all of a person's rights, and can limit opportunities for a person with ID to learn how to make decisions.

For these reasons, it's important to work together to find the right supports that respect a person's choices while helping a person to be safe.

Types of Supports

Informal supports – Family and friends can help a person with ID understand the issue, choose among options, and communicate a decision.

Person-centered planning – Person-centered planning is an ongoing process where a person and a group of people who care about the person come together. This "person-centered" team meets to focus on the person's vision for the future. The team helps identify ways for the person to develop relationships, participate in the community, increase control over their life, and develop the skills and abilities needed to achieve these goals. The team takes action to make sure that the strategies are implemented.

Money management – A person can assign control of some or all of their financial matters to someone else. Paperwork and court action are often involved. Options include:

- ◆ Representative payee (for Social Security / SSI payments)
- ◆ General power of attorney
- ◆ Trust or Special Needs Trust

Health-care decisions – The D.C. Health-Care Decisions Act allows a close family member or friend to make a health-care decision on behalf of a person who is incapacitated to make the decision – without going to court. Other options that may require legal help include:

- ◆ Living will
- ◆ Health-care power of attorney

Guardianship – Sometimes, a family member may hear that they need to be a guardian to stay involved with a person's life and protect the person from harm. But guardianship isn't for everyone:

- ◆ Guardianship removes many of a person's rights and freedoms.
- ◆ Guardianship can make it harder for a person to learn how to make decisions on their own.
- ◆ Being a guardian is a major responsibility. It requires time, cost and accountability.
- ◆ Obtaining guardianship is not quick. It involves going to court and can be costly.

Often, guardianship is a legal solution to personal issues that can be better handled in less intrusive ways. That's why most professionals who work with people with ID encourage families to make guardianship the last resort, not the first. Kinds of guardians include a health-care guardian, a limited guardian, and a full guardian.

Questions

Call Quality Trust for Individuals with Disabilities at 202-459-4004.