

Consent — What It Really Means

Consent can at times present sticky challenges to organizations and staff members. Often, the biggest hindrance comes from making the process more complex than necessary and forgetting about how important it is for people to learn from their life experiences and have the freedom to make mistakes.

What does consent really mean? And how can we best support individuals with intellectual and developmental disabilities when facing important decisions on whether or not to consent to a matter?

Quality in Practice

When supporting adults:

Think about how you come to decisions in your own life: Do you list pros and cons and different possibilities? Do you investigate a slew of options before finally deciding on something? How do you go through the process of consenting to/not consenting to something?

Consider these tactics when assisting others.

- Capacity should always be assumed. Start with the knowledge that this person makes decisions every single day. Assess how he or she makes those decisions, and how he or she lets you know about preferences – let this knowledge guide you in providing the appropriate resources and experiences to aid in decision-making.
- For consent to be truly informed, the information must be communicated in an effective way and in an understandable and accessible manner. The person must be able to make decisions, and the decisions should be voluntary.
- Engage in a process of asking and listening to achieve the right balance of support. Supply tailored information that complements the person's learning style with what she or he needs to know about the matter. Take a closer look into areas that the person is especially interested in learning more about.
- Get away from the concept that there is a “perfect choice or answer”. Help people come to their own conclusions, even when you may not be in full agreement.

- As needed for some individuals, provide more intense supports throughout the decision-making process, such as involving a guardian, a surrogate decision-maker, or an advocate (not affiliated with the organization) to assist them.
- Work with a Human Rights Committee in offering assistance and oversight, if there are additional areas of concern regarding a person's health, welfare or safety, or if any discussion emerges on rights limitations.
- When using written consent forms, ensure that the consent is time-limited, with a clear specificity and a well-defined purpose.
- Understand that the person has the right to rescind consent and support all stakeholders to be familiar with that process.
- Consent cannot be implied simply because an individual is involved in a particular program.

When supporting families with young children and children and youth:

- Specialists who provide supports to families with young children assist them best in this area when they anticipate their future needs. They are proactive in ensuring that the family is given quality information that is timely and fitting to their precise circumstances.
- As a child ages, his or her involvement in decisions grows and increases naturally.
- Therapists, specialists, and staff members stay in tune with the child's/youth's advances in independence and encourage their participation in order to nurture and develop emerging self-advocacy skills.