# Beneficiary Support Toolkit for Trust Professionals



# Chapter 2: Decision-Making

**How Will Decisions Be Made?**

People with disabilities must [make many daily and major life decisions](https://futureplanning.thearc.org/pages/learn/where-to-start/supporting-daily-and-major-life-decisions), just like people without disabilities. These decisions can range from making simple purchases to managing a budget to talking to a healthcare provider about medical care.

There are many options for supporting people with disabilities to make decisions throughout their life. Most people, including people with intellectual and developmental disabilities (IDD), can make day-to-day decisions, such as what to wear, eat, and do, on their own, ***without supports***. Additionally, most people, including people with IDD, make big, important decisions by asking the people they trust for advice. That is called ***supported decision-making***. Some people with disabilities want or need someone to make decisions for them. That is called ***substitute decision-making***.

Beneficiaries you support may have very different decision-making arrangements. These decision-making arrangements will shift based on a person’s skill level and ability and preferences. A beneficiary’s decision-making arrangement [may also shift](https://futureplanning.thearc.org/assets/Future%20Decision%20-%20Center%20for%20Future%20Planning-bfbeb59e1a0ac03013d58e3da8c96fd29f46d753cfa8ecd9c1cbe65267f6c8d2.pdf) as a part of growing up, because of illness (e.g., dementia), or as they get older.

While the trustee maintains sole discretion to decide how the trust is used, it is important to:

* Understand any decision-making arrangement a beneficiary and their family has in place
* Ensure all parties involved in decision-making are involved in decisions about the trust
* Keep beneficiaries engaged in discussions about their life and how resources will be used to help them achieve their goals, no matter the decision-making arrangement
* Ensure a trust supports the wishes of the beneficiary on how they want to live a good life

This chapter offers recommendations, tips, and tools you can use to learn about decision-making arrangements, ensure all are engaged in the decision-making process, and make sure a trust supports the beneficiary’s wishes and goals. We hope that these resources are helpful to you in your work.

**Learn about decision-making arrangements on day one.**

From the day you first meet with a prospective beneficiary and their family, start to learn about how they currently make decisions and want to make decisions in the future. Make sure to ask not only about how financial decisions are made but also how other decisions - like housing, health, and daily life – are made. Resources from the trust may need to be leveraged at various points to help support other life areas, so it is important that you know how many different types of decisions are made.

Make sure to ask what information the decision-maker(s) want from the trust. People’s preferences about how much information and what type of information they want or need may vary based on preferences and needs. As best possible, try to understand what type of information is needed to make a decision about how to request trust resources.

In addition to learning about how decisions are currently made, it is important to understand how decision-making may change in the future. As a beneficiary’s ability to make decisions increases, they may want to take on a more independent role in decision-making. Conversely, as a beneficiary gets older, they may want or need more support to make decisions. Take time to learn about what changes people anticipate to the decision-making process.



[This Toolkit includes a checklist you can use with a beneficiary and family to learn more about how decisions are made.](https://thearc.org/wp-content/uploads/2021/12/2.1-Learning-How-Decisions-Are-Made.docx)

**Ask for a beneficiary’s consent before sharing information with others.**

While a trust must share certain information with government and other oversight agencies, you should ask the beneficiary for their informed consent to share most other information with others. This applies to HIPAA information as well as any other information that is shared. It may be a good practice to gather a consent form at your initial meeting.

Even if a beneficiary has a guardian or power of attorney, it is a sign of respect to get consent from the beneficiary, with their legal decision-maker present, in addition to getting consent from the legal decision-maker. While legally, you may only need permission from a representative, it is still the beneficiary’s information that is being shared.

[Here are steps to take to gather informed consent from beneficiaries.](https://thearc.org/wp-content/uploads/2021/12/2.2-Gathering-Informed-Consent.docx)

**Make sure all staff understand these decision-making arrangements.**

Now that you know how a beneficiary and family makes decisions, ensure all other trust staff know and communicate with all those involved in decision-making. Communicating key information with all decision-makers can help ensure that you build and grow a positive, efficient relationship. Making sure all decision-makers have access to needed information makes it likelier you can receive faster and better-quality decisions from beneficiaries and their family when needed. It also can help you avoid receiving calls for information from decision-makers. [Chapter 1](https://thearc.org/wp-content/uploads/2021/12/1.0-How-Will-I-Communicate-with-the-Beneficiary-and-Their-Family.docx) provides more guidance on how you can make sure to create a system to promote clear, consistent, and effective communications.

**Prepare for the planning process, ensuring the beneficiary is at its heart.**



As you work with the beneficiary and any supporters to develop a plan, make sure it is clear that the beneficiary is at the heart of the planning process.

All people can communicate their wants and needs. Some may communicate verbally using complex language. Others may respond to simple questions. Some may be able to communicate nonverbally. Others may show you how they feel via their behavior. Regardless of method, every person can express wants and needs.

Make sure your planning process seeks guidance from the beneficiary to identify their goals for their life and understand their needs. This information is critical to decide how trust resources need to be used to help them achieve their goals and pay for their needs. Trusted family, friends, and supporters may also be able to help you brainstorm ways to amend your planning process to best engage the beneficiary.

[This checklist can help you review your planning process and identify ways you can engage all beneficiaries to lead their planning process.](https://thearc.org/wp-content/uploads/2021/12/2.3-Keeping-Beneficiaries-at-the-Center-of-a-Budget-Plan.docx)

**Make the decision the beneficiary would want, as much as you can.**

Trust professionals often face a challenging moment when weighing two factors around budget planning and decision-making:

* What is the trust’s duty of care to make sure the beneficiary’s quality of life is protected, and
* What extent can beneficiaries exercise their dignity of risk – to make their own decisions.

A special needs trust is not just a financial tool; for many, it is a way for people to fund their ***dreams.***

[Here is more information and examples to help you weigh duty of care and the dignity of risk](https://thearc.org/wp-content/uploads/2021/12/2.4-Weighing-Duty-of-Care-and-Dignity-of-Risk.docx).



**Check-in annually about decision-making arrangements.**

Everyone’s ability to make decisions changes across a lifetime, including people with 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 disabilities – especially people with Down syndrome - are at particular risk for dementia and Alzheimer’s as they get older. They may need more help from others to make decisions.

Unexpected things can happen at any time that affect people’s ability to make their own decisions. If plans aren’t in place, decision-making can become more limited, and people may have decisions made that don’t align with their goals.

Take time yearly to understand how beneficiaries and their families make decisions. Beneficiaries and families should assess the beneficiary’s ability and desire to make decisions and ensure that any arrangements are in line with what the beneficiary wants and needs. You can share [this website](https://futureplanning.thearc.org/pages/learn/where-to-start/supporting-daily-and-major-life-decisions) with beneficiaries to help them understand why this is important to do and consider options.

[This Toolkit includes a checklist on ways you can make sure you include this information – and gather any updates about changes in arrangements – from beneficiaries.](https://thearc.org/wp-content/uploads/2021/12/2.5-Updating-Decision-Making-Arrangements-and-Goals.docx)

**Report abusive, neglectful, or poor-quality substitute decision-makers.**

Much like trustees and trust administrators, guardians, conservators, and powers of attorney are entrusted to be good faith actors who help people achieve their best possible quality of life.

However, they are not supposed to make just the best financial decision or the best investment decision – they should be making the decisions the beneficiary **would want to make, if they were able to do so**. These decisions should be ones that support the beneficiary to live their best life and achieve their goals and passions.



If a beneficiary tells you or you observe that a guardian, power of attorney, conservator, or another supporter is not acting in the interest of the beneficiary, contact your state’s [protection and advocacy organization](http://www.ndrn.org/en/ndrn-member-agencies.html) to investigate the situation and potentially support the beneficiary to identify a better solution for them.

[This Toolkit includes a checklist that you can use to think through how to incorporate this observation and this potential reporting in your trust’s policy.](https://thearc.org/wp-content/uploads/2021/12/2.6-What-to-Do-with-a-Poor-Quality-Substitute-Decision-Maker.docx)

**Reflection Questions**

1. How do you currently gather information on how beneficiaries make decisions and how they want to make decisions in the future? Is there a way to improve this process?
2. How does your trust organization currently gather informed consent? What steps can be taken to improve how this occurs?
3. What steps do you take to engage the beneficiary in the planning process for the trust budget? How can you engage the beneficiary more effectively?
4. How frequently do you touch base with the beneficiary and their family about how decisions are made?
5. What does your trust organization’s policy state about identifying poor-quality or potentially abusive or neglectful decision-making supporters?

**Linked Resources**

* [Learning How Decisions Are Made](https://thearc.org/wp-content/uploads/2021/12/2.1-Learning-How-Decisions-Are-Made.docx)
* [Gathering Informed Consent](https://thearc.org/wp-content/uploads/2021/12/2.2-Gathering-Informed-Consent.docx)
* [Keeping Beneficiaries at the Center of a Plan](https://thearc.org/wp-content/uploads/2021/12/2.3-Keeping-Beneficiaries-at-the-Center-of-a-Budget-Plan.docx)
* [Weighing Duty of Care and Dignity of Risk](https://thearc.org/wp-content/uploads/2021/12/2.4-Weighing-Duty-of-Care-and-Dignity-of-Risk.docx)
* [Updating Decision-Making Arrangements and Goals](https://thearc.org/wp-content/uploads/2021/12/2.5-Updating-Decision-Making-Arrangements-and-Goals.docx)
* [What to Do With a Poor-Quality Substitute Decision-Maker](https://thearc.org/wp-content/uploads/2021/12/2.6-What-to-Do-with-a-Poor-Quality-Substitute-Decision-Maker.docx)

**Share With Us**

Did any of these tips and resources spark a memory or story you want to share, or a resource or tool you need? [Complete this form to contact us and share your ideas](https://thearcus.surveymonkey.com/r/7F5N5DC)!

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