



Making *Supporting People in Decision Making* Choices

This is one of a series of guides that provide an introduction and orientation to using a personal outcome approach to measure quality in services and supports for people with disabilities. Titles in the series include:

Designing Quality: Responsiveness to the Individual

Thinking About Outcomes: An Orientation Guide

Making Choices: Supporting People in Decision Making

Enhancing Rights: A Proactive Approach

The Council on Quality and Leadership is dedicated to ensuring that people with disabilities have full and abundant lives. The Council works with service and support providers to enhance and support their efforts towards quality improvement.

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THE IMPORTANCE OF CHOICE

Choice is the foundation on which people build all the outcomes in their lives. The choices that people make direct their lives and reveal what is important to them. The *Personal Outcome Measures*, published in 1997 by The Council on Quality and Leadership in Supports for People with Disabilities (The Council), recognizes and emphasizes choice and decision making as key variables. Each person defines the outcomes according to personal preferences and desires. People are more likely to be successful at choosing and achieving personal goals if they can select goals that are personally important to them.

Friendships revolve around certain choices. The process of obtaining optimal health care is filled with choices, many of them very difficult to make. Where to work, how to get to work, and how to spend your day or evening are all important choices. Throughout our lives we make many choices. These choices express our priorities and uniqueness as people.



Without experience, there can be no real choice.

FREEDOM OF CHOICE

People's choices are limited in a variety of ways. For instance, choices can be limited by the number of people you live with, the job market in a particular area, and limitations imposed by the people and services you depend on for support. People with disabilities often have extremely limited choices. Sometimes these limits occur because of group living. Other times limits are imposed because of the assumption that a person cannot make a choice. The belief that all persons can make choices or indicate preferences in their lives is the philosophical basis of the *Personal Outcome Measures*.

Respecting a person's freedom of choice does not mean ignoring responsibility for supporting that person. The service provider must take great care to balance respect for individual choice with the responsibility to protect people from harm. People have the right to make decisions and often learn valuable lessons from mistakes. Supporting people to exercise this right involves teaching decision-making skills, assisting them to think through difficult choices, and providing them a range of alternatives.

BALANCING CHOICE WITH RESPONSIBILITY

Increasing people's choices does not mean allowing them to act without regard for other people or their own safety. Choice must be balanced with reality and responsibility. By providing the necessary skills and supports, we can help people explore choices and brainstorm alternatives.

This guide will assist persons with disabilities, service providers, and other interested people involved in the choice-making process. Using this guide will enhance understanding of:

- ▶ **the dynamics of choice**
- ▶ **a framework for supporting choice**
- ▶ **how to listen to people's choices**
- ▶ **how to handle difficult choices**

The Dynamics of Choice

Choice is complex. It encompasses many aspects of an individual's personality and life experiences. Choice requires acknowledgment of its emotional aspects, decision-making skills, and the opportunity to choose different courses of action and

learn from mistakes. By means of six simple exercises, the balance of this guide provides a look at the various dimensions of choice.

DIRECT EXPERIENCE AND MAKING CHOICES

EXERCISE 1.

Think of a choice you've made recently. It can be a simple choice such as what to eat for breakfast, or a more involved choice such as what kind of car to buy. List any previous experiences you relied on to make this choice. How did each experience influence your final choice?

Amount of experience: The amount of direct experience we bring to a situation affects our decision-making process. If we have more experience in a given situation, we have more confidence. We may have so much confidence that we barely give the choice any thought at all. If you eat breakfast every morning, you have had a lot of experience in picking breakfast foods. Chances are, you give very little thought to this choice. However, if you have purchased only two cars in your life, you have limited experience, and probably less confidence about this decision.

Type of experience: The type of experience you have with choice may also affect your decision-making ability. If you have had many positive experiences in making career choices, then you will likely have a great deal of confidence when choosing your next job.

Sometimes our experiences with choice are very negative. This often happens in group-living situations where people have limited options about matters such as when to shower, when to eat supper, where to sleep, or keep their possessions. If a person is offered a choice and then is told his or her choice is not an option, he or she is less likely to venture to make a choice again.

INDIRECT EXPERIENCE AND MAKING CHOICES

EXERCISE 2.

Imagine you are planning a vacation cruise and need to decide between going to the Caribbean or Alaska. You have never been to either place before and neither have any of your friends. A first step in making up for your lack of direct knowledge

would be to list all the ways you could find out about these places without actually experiencing them.

Life presents us with opportunities to do new things almost every day, although the new experience might not always be a cruise! We may have no previous experience with a choice we are faced with, but there are ways we can get assistance with that choice. Some people may have more limited experience than others. For example, a person who has lived in a hospital or institution may have had very limited choice-making experience. Living in only one type of community may also limit a person's experience with certain types of choices. Consider the example of Linda and Karen below:

Linda grew up on a farm near a town of only about a hundred people. She had very little experience with city living. Karen grew up in a small city and had minimal experience with living on a farm. When Karen would go the country to visit Linda's house, she always experienced something a little bit different. For instance, in her own house in the city, Karen would get up as soon as she finished dinner to clean her plate. She would do this by scraping all the food into one garbage container. When she visited Linda's house, she started to do this but was quickly interrupted by Linda's mother who directed her to put leftover food in the compost heap, paper in the paper burn bin, and any other trash in the garbage bag. The simple decision of how to clean her plate was complicated by a lack of experience. The point is that a choice that may make sense in one environment may not be the best choice in a different environment.

Experience, whether direct or indirect, is a critical part of making choices. We can gain experience through sharing other people's experiences; through books, pictures, and videos; and occasionally through simulations. Experience can also be gained by trying something new and relying on someone else for support during that activity. Without experience, there can be no real choice.



*For important choices and decisions, many people
look to friends and family for advice and assistance.*

Opportunity is closely linked with experience. Lacking the opportunity to make choices prevents us from developing the skills necessary to make better choices in the future.

EXERCISE 3.

Think about how you started your day and the choices that you had to make (although many were perhaps unconscious choices). Jot down the action on the left side below and the choices on the right side. An example is provided to help you get started:

Action	Choices
1. Wake-up	Turn off the alarm or hit the snooze button? How often to hit the snooze button? Which side of the bed to get out on? Should I put on slippers and a robe?
2. _____	_____ _____ _____
3. _____	_____ _____ _____

Next, think about the limitations imposed on your choices. If you live with other people, you may need to choose the time you wake up based on when you can use the shower. If you rely on someone else for a ride to work, you have to consider what time that person will pick you up. Your choice of breakfast food may be limited by your budget. Are any of these limitations the result of a disability? Are these arbitrary limitations? How can these limitations be decreased?

Decreasing the limitations greatly increases the number of choices a person can make. This increase in choices allows a person to gain more experience in choice-making and to make continually better choices.

A Framework for Supporting Choice

PEOPLE AS SOURCES OF ADVICE FOR CHOICE-MAKING

EXERCISE 4.

Think of a decision you made recently for which you sought some advice. Make a list of all the people you talked to, grouping them according to their relationship to you (friends, family, etc.). Thinking about your recent decision, ask yourself the four questions listed below:

1. Who did I ask for advice? (*friends, family, professionals, others*)

2. What questions did I ask?

3. How was this helpful to me?

4. Who made the final decision?

People make choices in different ways. For important choices and decisions, many people look to friends and family for advice and assistance. Some people seek the assistance of professionals to help with difficult or technical decisions. Some people prefer to make decisions alone, without consulting anyone. There may be occasions where people rely on religious beliefs or tradition to guide certain choices. Most people look for support of some type.

The issue of social context for decision-making and choice challenges service systems supporting people with disabilities. If people have been disconnected from their natural supports, they have to depend on staff to support them. The reality is that we can support people in decision making by providing information and helping them to gain experience. Because staff cannot replace voluntary personal connections, social integration and family connections are critical supports for most people when making choices in life.

CREATIVITY

EXERCISE 5.

Think about an important decision you made recently, such as taking a new job, buying a new car, or deciding where to go on vacation. List all the options you considered before making your choice. How did you know about those options? How many options did you list? What factors did you consider in selecting or rejecting each option? How did you finally make a choice?

People's choices are often limited when options are not explored fully. If a person is presented with the choice of accepting a job at a fast-food restaurant or continuing to work at a sheltered workshop, all possible options have not been explored. It is challenging to discover all the options available to a person; thus, creativity is essential to choice-making.

Creativity has special relevance to supporting choices within the service process. It reminds us that we need to be flexible and accommodate a degree of uncertainty while supporting personal choice. It may be difficult to feel certain that what people say they want today is what they will want tomorrow. We must direct supports at the process of discovery and not at finding the "one and only answer."

Using creativity requires forming relationships with people. Through relationships we can learn about a person and his or her preferences. Creativity also involves brainstorming about possible options for each situation. Each person is assisted in discovering options that match his or her priorities and preferences before selecting an option suited to his or her individual needs and desires.

The Process of Choice

The process of choice is different for each individual. Some people make choices quickly; others are slow, deliberate thinkers. The process of choice itself involves many "choices." Some people choose to seek advice from everyone they know before making a choice; others contemplate possible choices alone and in silence. There is no "right" way to make a choice. The "personal quest" process described on page 11 is one way of making better decisions.



Supporting other people in their choices

*involves a process of discovering and supporting
the priorities of another individual.*

A PERSONAL QUEST: DISCOVERING WHAT IS MOST IMPORTANT

The traditional planning process involves using a team to set goals and objectives for a person. Unfortunately, these goals may have nothing to do with what the person considers important. Discovering what is really important to someone involves taking the time to learn from that person.

Assisting people as they develop a focus or a vision statement gets to the core of what is personally important to them. This focus cannot be developed for the person. It is a reflection of the person. Once it is developed, it can then be used as a yardstick for measuring all choices. When faced with a choice, someone with a focus can ask: Will this choice move me closer to my ultimate goal? Will this choice deflect me from my personal mission?

Once you have focused on how you want to shape your future, you are ready to consider specific choices. Choices are best made by exploring all aspects of the situation as it affects a person. Intellectual, emotional, social, and spiritual aspects can be explored for any choice. You can help yourself do this by visualizing a part of your body for each aspect in the following way:

Head: Visualize your head when thinking about the logical and practical aspects of your choice. This kind of thinking also involves some of the judgment needed in making choices. Questions you might ask include: What has experience taught me about this choice? Can I afford this choice? Which choice helps me to attain things that I need? Is this the best possible choice for my life right now? How will this choice affect me in one year, five years, ten years? What are all my possible options?

Heart: Your heart is emblematic of the emotional aspects of your choice. Almost every choice has an emotional aspect. Often the emotions are based on experiences or fears about the future. Denying the emotional aspect of the choice will cloud your thinking and decrease the chances that your choice will be the best possible one for you. Ask yourself some of the following questions: How do I feel about this choice? How will I feel tomorrow about this choice? Am I feeling anxious? What are my fears around this choice? Am I attempting to fulfill a real need with this choice or just a wish? What is my wish? Is this the best way to fulfill it? What does my gut tell me about this choice?

Hands: The hands represent the social aspect of all choices. Most of our choices involve other people. If we live with other people, our choices may involve their lives more intimately. We must consider how our choices affect the lives of other people. Ask yourself some of the following questions: Who else may be involved in my choice? Are the choices of others limited because of my choice? Is there anyone whose advice or permission I should seek concerning this choice?

Spirit: The spiritual aspect of your choice involves reflecting on how this choice affects the overall direction of your life. Earlier in this guide, you read that people need to take time to explore the overall direction or vision for their lives. Once you have that direction, you need to measure your major choices against that vision so that your everyday actions and choices will help you to attain your ultimate goals in life.

Feet: Carefully combine all of the above considerations, make a choice, and act on it. In other words, get your feet moving! Think of the action as a carefully thought-out experiment. Most choices are not irreversible. When we think of choices as irrevocable, we can be frozen by the fear of the perceived enormity of the decision. Think of this step as assisting you to make the best choice possible. Keep in mind that you can make a change, if a better choice presents itself later.

The personal quest process can be invaluable in making choices and in supporting other people in making choices. The steps help focus on a person's individual priorities when making choices. We cannot create priorities for people; only they can discover their own priorities.

Adapted from "Yes" or "No:" The Guide to Better Decisions, by Spencer Johnson, M.D. New York: HarperCollins, 1992, Page 12.

AVOID "HOBSON'S CHOICE":

English history tells of a seventeenth-century stable master, Thomas Hobson, who would make every customer take the horse nearest the door, regardless of the customer's preference. More than 300 years later, people still use the term "Hobson's Choice" to describe a supposed choice that's really no choice at all. People with disabilities are often treated this way within service systems. For example, there may be only one job available for a person to consider. The

person is “tried” in this job and it doesn’t work out. The person is then sent back to a vocational program or workshop because “it’s the only other choice.”

People should be supported to experiment with a variety of options before making a choice. Sometimes, a choice can be presented as an experiment rather than as something permanent. Providing someone with only one course of action, and assuming that it is the person’s choice because he or she did not reject the offer, is nothing more than playing a game of “Hobson’s Choice.”

Communicating Choices

Sometimes it is difficult to understand a person’s choice because we have difficulty communicating with the person. When working to support a person in his or her choices, it is important to know the person’s individual communication style. Some people communicate effectively through speech, some use sign language, others use adaptive devices, and still others communicate effectively through actions.

If you are assisting a person who has no verbal or assisted communication abilities you must use effective observation skills to understand the choices that person expresses. Preferences for which side of the body he or she wants to lie on, preferred support staff, preferred food consistency, and choices of friends can provide service providers with insight into the person’s unique personality. Using these indications of someone’s preferences, a service provider can then put forth alternatives and observe the person’s reactions. These reactions can help the service provider understand the person’s current choice and to assist him or her in making future choices.

When someone can communicate using words or symbols, staff need to listen very carefully to the person’s words and nonverbal messages. The use of reflective techniques and providing feedback to the person on what the staff person is hearing will help to make the choice clearer to the staff and assist the person in making decisions.

Choices and Natural Learning

People learn best in natural settings. It is difficult to learn skills in the abstract. If a person has a developmental disability, it is often preferable to learn a skill in a natural setting. Requiring people to master specific skills before living in a home or apartment ignores the undeniable importance of natural learning. People with cognitive difficulties often have difficulty generalizing learning from one setting to another. Thus, the best way to teach a person is in the setting where the need for the skill will occur. For example, it is best to learn banking skills at the local bank, cooking skills using the stove of one's apartment, and pedestrian skills while using the community's streets.

Realities and Risks

THE NECESSITY OF RISK

EXERCISE 6.

Think about a choice you made that involved a risk to your safety and the stability of your life. An example might be living alone in an apartment when others thought you weren't ready for it. Other examples might be wanting to hike the Appalachian Trail alone or going white-water rafting on difficult rapids. What factors were involved in deciding to take the risk? Did you seek advice? What did you learn from this choice? Did you receive support before, during, and after your choice?

In attempting to keep someone "safe," others often deprive an individual of the ability and the rewards of taking risks in life. People learn by making life decisions of increasing significance and risk.

When people take risks and experience failure, the type of support they receive helps to determine the learning that will result from the experience. Support should help the person learn from the mistake and make a better decision next time. "Failure" is a learning experience, and learning includes finding out about the consequences of failure and success.

Providing support to people when they are taking risks does not mean that they should be allowed to fail in major ways for the sake of "experience." People should not have to take major risks without previous learning and without support if they make a mistake.

DEALING WITH DIFFICULT CHOICES

Supporting other people's choices, while keeping our own feelings in check, is a challenge. It becomes even more complicated in a service setting when we're concerned with providing supports that will protect people from unreasonable risk and harm.

How can we respect individual decisions while protecting people from harm? One way is to focus on understanding "why" someone is making a particular choice. Steps to accomplish this are outlined below:

1. *Attempt to learn why this choice is important to the person.*
 - a. Ask the person questions about the practicality of the choice.
 - b. Ask questions that focus on the emotional aspects of the choice.
 - c. Ask what social support is involved with the choice.
 - d. Ask the person how this choice will contribute to his or her goals.
 - e. Finally, offer the person assistance to identify as many alternatives as possible to the decision.

2. *Look more closely at your own reservations about the person's choice.*
 - a. List the practical reasons why you feel that the choice is not in the person's best interest.
 - b. Look at your own emotional reasons for opposing the person's choice. Are you more worried about the person's safety or about your job or liability? Do your emotions support the person's decision? Be honest and open with yourself.
 - c. What other people are involved in the decision? Are you concerned about your supervisor's reaction?
 - d. What is your ultimate goal in supporting the person?
 - e. Finally, list for yourself the number and range of options available to the person.

Complete this process with the person you are supporting. Share your feelings with the person and discuss your fears. Avoid judging the person's choice – be honest if you cannot support it. When communicated honestly, disagreement can convey respect.

Help the person to brainstorm alternatives to this choice. What are other ways of looking at this decision? Ask for as many alternatives as possible without judging

any of the alternatives or the choice that the person has already expressed. Ask the person his or her feelings about each choice. During this process, the person may change his or her mind. If the person doesn't change his or her mind, the choice should be respected and you should support the person through the consequences of that choice. If you or your organization cannot support the person's choice, be honest about it and present the consequences of the person's decision in terms of your ability to continue to provide support.

Conclusion

The choices that we and others make indicate our highly individual priorities and preferences. Supporting other people in their choices involves a process of discovering and supporting the priorities of another individual. This can be both challenging and rewarding.

Many people with disabilities have not been given the opportunity to make choices for themselves. Other people have made choices for them, often with the person's best interests in mind. This lack of experience may cause people to not express their opinions and rely on others to make decisions for them. People may need support to learn to be assertive and to learn the skills involved in making choices. The process of providing this support involves:

- ▶ **Forming a relationship with the person — Helping the person explore the practical, emotional, social, and spiritual aspects of choices**
- ▶ **Providing the person with opportunities to make more choices and to receive feedback on those choices**
- ▶ **Being creative**
- ▶ **Being attentive to the person's verbal and nonverbal communication**
- ▶ **Supporting risks for the person in a caring, responsible way**
- ▶ **Helping the person explore all the aspects and options involved with difficult choices**

Through this caring and creative process, people can experience more choice in their lives and increase the personal skill and comfort with which they make choices.

Personal Outcome Measures

IDENTITY

- People choose personal goals.
- People choose where and with whom they live.
- People choose where they work.
- People have intimate relationships.
- People are satisfied with services.
- People are satisfied with their personal life situations.

AUTONOMY

- People choose their daily routine.
- People have time, space and opportunity for privacy.
- People decide when to share personal information.
- People use their environments.

AFFILIATION

- People live in integrated environments.
- People participate in the life of the community.
- People interact with other members of the community.
- People perform different social roles.
- People have friends.
- People are respected.

ATTAINMENT

- People choose services.
- People realize personal goals.

SAFEGUARDS

- People are connected to natural support networks.
- People are safe.

RIGHTS

- People exercise rights.
- People are treated fairly.

HEALTH AND WELLNESS

- People have the best possible health.
- People are free from abuse and neglect.
- People experience continuity and security.



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