

ASSISTED DECISION- MAKING: EMPOWERING INDIVIDUALS WITH DISABILITIES

A TRAINING GUIDE FOR SUPPORTS,
FRIENDS, AND FAMILY

*"The right to make decisions is
the foundation of human
dignity."*

JUDITH SNOW, DISABILITY ADVOCATE



By Korrie Crabtree

What is Assisted Decision-Making?

Assisted decision-making is a process that helps individuals with disabilities make informed choices about their lives. It focuses on providing the necessary support to help the individual to understand their options, express their preferences, and make decisions in ways that respect their autonomy and dignity.

Why is Assisted Decision-Making So Important?

- **Promotes independence** by ensuring individuals have the opportunity to make decisions for themselves.
- **Respects human rights**, affirming that everyone, including individuals with disabilities, has the right to make decisions about their own lives.
- **Fosters self-confidence** and empowers individuals to become more involved in their life choices and day-to-day decisions.

Key Strategies

1. Simplify Information

Break down complex information into clear, easy-to-understand terms. Use visuals, diagrams, or videos to help explain options.

2. Offer Choices, Not Directions

Whenever possible, present options and explain the potential outcomes of each, but let the individual decide which path they prefer.

3. Encourage Self-Expression

Create opportunities for the person to express their thoughts, feelings, and preferences. Use open-ended questions and give them time to respond.

4. Provide Emotional Support

Making decisions can be overwhelming. Be there to listen, validate their feelings, and provide reassurance.

5. Respect Timing

Give the person time to process information and make decisions. Decision-making shouldn't be rushed.

Understanding Key Principles

Empowering the Individual to Lead

At the heart of assisted decision-making is a deep respect for an individual's autonomy. This means actively encouraging the person to lead the decision-making process, providing support only when necessary. The goal is not to take over or make decisions on their behalf but to ensure they remain at the center of their choices.

● What does this look like in practice?

- Encouraging individuals to articulate their preferences.
- Offering information and support in a way that honors their ability to make decisions.
- Ensuring they are comfortable asking questions and seeking clarification when needed.

Autonomy is essential to maintaining dignity and fostering a sense of control in an individual's life. The more we respect this, the more they can thrive in making their own choices.

Respect for Autonomy

Helping Individuals Make Well-Informed Decisions

Informed choice means providing clear, accessible, and relevant information about all available options so the individual can make decisions that align with their values and preferences. This includes presenting the potential **benefits** and **risks** of each option in a way that is easy to understand.

● How to Support Informed Decision-Making:

- **Provide comprehensive information:** Break down complex topics into digestible parts and use language that is accessible.
- **Explain risks and benefits:** Help individuals weigh the pros and cons, making sure to highlight the potential outcomes of each choice.
- **Use various formats:** Offer information in written, verbal, or visual formats based on the individual's preferences and needs.

When individuals understand their options fully, they can make choices that are true to themselves, ensuring their decisions reflect their personal goals.

Informed Choices

Guidance, Not Control

Assisted decision-making is about **supporting** individuals, not replacing their decisions. By collaborating with the individual, we provide the tools and guidance necessary for them to explore their options and express their preferences.

● What This Involves:

- **Listening actively:** Create a safe space for individuals to share their thoughts and concerns without judgment.
- **Clarifying options together:** Help break down choices, exploring the possibilities together to help the individual understand the outcomes of each.
- **Encouraging self-expression:** Support individuals in articulating what they truly want, even if that means they might need more time to decide.

Rather than directing their choices, the focus is on collaboration. The individual remains the primary decision-maker, with you offering support as they navigate their options.

Support and Collaboration

Gradual Transition to Independence

Building Confidence for Self-Determination

The ultimate aim of assisted decision-making is to help individuals build the **skills** and **confidence** they need to make independent decisions over time. This approach promotes **empowerment**, ensuring that individuals feel capable and supported in managing their decisions as they become more experienced.

● Steps Toward Independence:

- **Start small:** Begin with decisions that are less complex and gradually work toward more significant ones.
- **Provide constructive feedback:** Offer positive reinforcement and gentle guidance to help individuals learn from their choices.
- **Encourage self-reflection:** Prompt individuals to reflect on their decisions and outcomes to build awareness and confidence in their abilities.

By gradually increasing the individual's involvement in decision-making, we nurture their ability to stand on their own and trust their judgment, preparing them for more self-directed choices in the future.



Your Role in Supporting Decision-Making

Empowering, Not Controlling

As a supporter—whether as a friend, family member, or caregiver—your role is to empower the individual to make their own decisions while providing the necessary support and guidance. This means standing by their side as they navigate choices, all while respecting their voice, preferences, and rights.

● Your Key Responsibilities:

- **Provide information clearly:** Present all relevant options in an understandable way, using language or formats that make sense to the individual.
- **Encourage active participation:** Involve the individual in the decision-making process by helping them express their thoughts and preferences.
- **Offer guidance, not control:** While it's important to offer assistance when necessary, remember that the ultimate decision should remain with the individual.

Your role is to facilitate and support, not to take over or make choices for them. This helps preserve the individual's autonomy and ensures their decisions are truly their own.

1. Communication Clear, Accessible Information

Core Responsibilities of a Supporter

Effective communication is key to empowering the individual. It's your responsibility to ensure that any information shared is **clear**, **concise**, and **accessible**.

- **Use plain language:** Avoid jargon or complex terminology. Speak in a way that is easy for the person to understand.
- **Provide visual aids:** Depending on the individual's needs, using pictures, charts, or diagrams may help convey important details.
- **Repeat and clarify:** Some individuals may need additional explanations or time to understand. Be patient and willing to rephrase when necessary.

Making sure the individual fully understands their options is a foundational step in helping them make an informed choice.

2. Patience: Allow Time for Reflection and Expression

Decision-making is a process that requires time. It's crucial to be patient and give the individual space to **process** information and **express** their thoughts.

How to Show Patience:

Wait for the individual to respond: Give them ample time to think about the options without rushing them.

Listen attentively: Ensure the person feels heard by giving them the time and attention they need to share their preferences.

Be supportive, not pushy: Encourage dialogue, but avoid pressuring the individual into making a decision before they're ready.

Allowing individuals to take their time fosters a sense of control and respect for their own decision-making process.

3. Respect for Choices Honoring the Individual's Right to Decide

Even when you may not agree with the individual's choice, it's vital to respect their right to make decisions about their own life. Supporting someone means acknowledging that their preferences and values should be the guiding force in their decision-making.

● How to Respect Choices:

- **Avoid judgment:** Refrain from expressing disapproval or judgment about the individual's decisions.
- **Provide emotional support:** Whether you agree or not, be there for the individual in a non-judgmental way, offering emotional support and understanding.
- **Validate their decision-making:** Even if the outcome isn't what you would have chosen, acknowledge that they are the ones who will live with the results of their decision.

Respecting the individual's choices, no matter how they align with your personal beliefs, is crucial in helping them maintain their autonomy and dignity.



Common Barriers to Assisted Decision-Making

- **Lack of Understanding:** Sometimes, individuals may struggle to process or understand complex information.
 - **Solution:** Use clear, simple language and visual aids to make information accessible.
- **Fear of Consequences:** The individual may fear making the "wrong" choice or facing negative consequences.
 - **Solution:** Help them understand that making decisions is a learning process, and mistakes can be opportunities for growth.
- **Over-reliance on Others:** Some individuals may rely too heavily on family or support staff to make decisions for them.
 - **Solution:** Encourage independent thinking by presenting options and guiding the decision-making process rather than making decisions for them.
- **Personal or Cultural Differences:** The individual may have different values or cultural preferences.
 - **Solution:** Be open and respectful of these values, and ensure that the choices align with the individual's own beliefs and preferences.

Encouraging Growth & Independence



Building Confidence in Decision-Making

Support the individual in making small decisions and gradually encourage them to take on more complex choices as they gain confidence. Over time, they will develop skills that help them make informed, independent decisions. **Encouraging Self-Advocacy**

Empower individuals to speak up for themselves and advocate for their needs. Help them practice self-advocacy skills by:

- Encouraging them to express their opinions.
- Practicing decision-making together.
- Supporting them in speaking directly to professionals or service providers when possible.

Scenario 1: Choosing a Healthcare Provider

John has an intellectual disability and is due for a routine medical check-up. His family is considering which doctor would be the best for him. Instead of making the choice for John, the family:

- Gathers information about the doctors available (e.g., specialties, experience).
- Explains the options to John in a way that is easy to understand.
- Encourages John to share his preferences, such as which doctor he feels more comfortable with.
- Supports John in scheduling the appointment with his preferred provider.

Scenario 2: Deciding Where to Live

Sara, who has a physical disability, is considering moving to a new apartment. She has a few options, but she is unsure which one would be the best fit. Her support person:

- Provides details about each apartment (location, accessibility, cost).
- Helps Sara weigh the pros and cons of each option.
- Gives Sara time to ask questions and reflect on her priorities (e.g., proximity to family, accessibility features).
- Respects her decision, even if it differs from their own preference.

Scenario 3: Selecting a Job or Volunteer Opportunity

Carlos, who has a developmental disability, is interested in finding a part-time job or volunteer opportunity. His job coach helps him consider his options by:

- Discussing Carlos' strengths, skills, and interests to find suitable roles.
- Presenting a few opportunities that match his preferences (e.g., working with animals, customer service).
- Encouraging Carlos to tour the workplaces or talk to employees if possible to understand the environment.
- Supporting Carlos in applying for the position he is most interested in, and practicing how to ask questions or prepare for an interview.

Scenario 4: Choosing a Hobby or Activity

Lily, who has a developmental delay, wants to try a new hobby, but she feels unsure of what she might enjoy.

Her support worker:

- Gathers information about different activities available in the community (e.g., art classes, sports, social clubs).
- Describes the activities in simple terms, highlighting what each one involves.
- Encourages Lily to explore the options by attending a few trial sessions or meetings.
- Asks Lily for feedback after trying an activity to see which ones she enjoys most and feels comfortable with.

Scenario 5: Planning a Vacation

David, who has an intellectual disability, is excited about going on vacation with his family. To help him make decisions about the trip, his family:

- Provides a few destination options, explaining the highlights of each one (e.g., beach, theme parks, nature trips).
- Discusses his interests, such as whether he enjoys nature, adventure, or relaxing activities.
- Guides David in considering the logistics (e.g., travel time, accessibility, accommodations).
- Encourages David to participate in planning the daily itinerary, ensuring that his preferences are included.

Scenario 6: Creating a Budget

Emily, who has an intellectual disability, is learning how to manage her own finances. Her caseworker helps her with budgeting by:

- Breaking down the process into simple steps (e.g., tracking income, identifying expenses).
- Discussing her priorities, such as saving for a special event or managing monthly bills.
- Showing Emily how to track her spending and set limits for different categories (e.g., food, entertainment).

Reviewing the budget together regularly and making adjustments based on her needs and progress.

Scenario 7: Choosing a Meal Plan

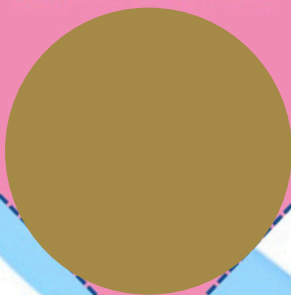
Max, who has a developmental disability, is learning how to plan meals and cook independently. His family supports him by:

- Offering several easy-to-make meal ideas based on his taste preferences and dietary needs.
- Helping him create a shopping list and explaining how to make choices at the store.
- Encouraging Max to practice preparing a meal, with guidance if needed.
- Reviewing the meal plan together each week, allowing Max to express what he liked or didn't like, and making changes as needed.



Conclusion: Your Role is Key

Assisted decision-making is about empowering individuals with disabilities to make choices that are true to their values, preferences, and goals. By offering support, providing information, and encouraging independence, you help create an environment where the individual feels respected and empowered to make their own decisions.



Increased Empowerment and Self-Determination *80% of individuals with disabilities who received support in decision-making reported feeling more empowered and confident in their ability to make choices about their lives.*

- **Source:** National Disability Rights Network, "A Fair Hearing: The Impact of Supported Decision-Making" (2017).

Improved Quality of Life *Individuals with disabilities who engage in supported decision-making experience a significant improvement in their quality of life, with 70% reporting higher satisfaction with life decisions.*

- **Source:** National Council on Disability, "The State of Disability in America: A Look at Supported Decision-Making" (2018).

Reduction in Guardianship *States with more widespread use of assisted decision-making have seen a 30% decrease in the need for full guardianship among individuals with intellectual and developmental disabilities.*

- **Source:** American Bar Association, "Supported Decision-Making: A Guide for Legal Practitioners" (2020).

Improved Health Outcomes *Studies show that individuals with disabilities who have access to decision-making support have better health outcomes, with 65% reporting better experiences in managing health care choices.*

- **Source:** Disability Rights Education & Defense Fund, "Health Care Access and the Role of Decision-Making Supports" (2019).

Positive Impact on Employment *Over 60% of individuals with disabilities who are involved in decision-making about their careers or work environment report higher job satisfaction and career success.*

- **Source:** U.S. Department of Labor, "Employment of People with Disabilities: Empowering Workers Through Supported Decision-Making" (2021).

