

Employment and Employment Supports: A Guide to Ensuring Informed Choice for Individuals with Disabilities

by David Hoff and Nicholas Holz

“Listen to our dreams about having a job. We want to work just like others.”

-Stirling Peebles,

Green Mountain Self-Advocates

As individuals with disabilities consider their employment options, questions often arise: Does the person want to work in competitive integrated employment? What kind of a job do they want? What are their career interests? And who is really making the decision: Is it the individual, or others on their behalf?

As people with disabilities consider their options and future direction in terms of employment, it is important that they do so within a process that puts them in the driver’s seat in terms of decision-making. This process must ensure they have the necessary information to make the choice they feel is the right one for them, embracing not just choice, but informed choice.

But what is “informed choice”? And how we do ensure that a choice is truly “informed” and fully reflective of the individual’s preferences?

This publication answers these questions. In it, we provide a guide to decision-making regarding employment and related services and supports, through a process where individuals understand their options, and make choices and decisions that are fully reflective of their own interests and preferences.

Informed Choice and Employment: Overview

What is informed choice?

Informed choice is the process of choosing from options based on accurate information, knowledge, and experiences.

Core principles of choice

- ▶ **Everyone is capable of making choices:** Everyone, regardless of their limitations, is capable of making choices, and needs opportunity, experience, and support to do so.
- ▶ **Choices are not unlimited:** Choice does not mean an individual can do whatever they want. Choice means selecting among available options, and clearly defining what those options are.
- ▶ **Choices have consequences:** And it is important to clearly understand what those consequences are.
- ▶ **All choices aren’t equal:** Choices are made within the overall context of cultural and societal expectations. As a result, some choices are viewed as more acceptable and more positive than others.

Ensuring a choice that is truly informed

Like all of us, individuals with disabilities have the right to make choices over where they work and how they spend their days. However, people with disabilities too often have limited experiences on which to base choices, combined with lives in which well-intended professionals and family members have made choices on their behalf or had undue influence on their decisions.

**Informed choice is not:
“Do you want to work? Yes or no?”**

Studies have found that, when given repeated opportunities to make a choice and act upon that choice, through observing or trying jobs in the community, individuals with severe disabilities clearly express their vocational preferences, which often differ from what their caregivers recommend or presume is their choice (Martin et al., 2005).

As a result, informed choice requires more than simply asking an individual whether or not they want to work, and it is not a simple yes or no conversation. It requires a deliberate and structured experiential process that puts the individual in a decision-making role, with sufficient experience and exposure to make a well-informed decision.

What does this mean in terms of employment?

Individuals with disabilities who are considering their employment and service options should have the opportunity to make a fully informed decision about whether they want to work in integrated community employment and what type of job they want. To make that decision, the person may need assistance in understanding the benefits that work can bring to their life, such as new relationships, money, control, health insurance, and a sense of self-worth.

The person should also understand the responsibilities involved in working and how it will change their day-to-day routine. The result of this decision should always reflect the person's preferences rather than what others think they should do.

Choice and publicly funded services

Via laws and policies, government at the federal, state, and local level will often define the preferred choices available to individuals receiving publicly funded services. With the Americans with Disabilities Act as a basis, through federal and state policies, government has made clear that integration and inclusion of people with disabilities into mainstream society and within the general workforce is preferred.

Government is under no obligation to fund segregated service options and provide them as a choice. If segregated service options are available, they can be among the choices that an individual can consider. However, government can still clearly indicate that segregated options are not preferred, and can place limits on or discourage their use.

Informed choice in the context of Employment First

Employment First means employment in the community is the preferred option for individuals with disabilities in terms of services and supports. As of 2020, thirty-eight states have Employment First policies that prioritize community employment over other options. Informed choice is a critical component of Employment First, requiring

“Everybody else in life gets the opportunity to make mistakes. You go out on your own, but because disabled people are often sheltered and other people are making decisions for us, we don’t have those opportunities to live completely wholly in that way.”

—Andraéa LaVant, Impact Producer, Crip Camp

a thoughtful and comprehensive process for individuals to fully consider employment in the community over other options (not working, sheltered employment, non-work day programs, etc.).

The challenges of informed choice

The ability to make informed choices is a skill and habit built over time. Lack of self-determination and self-advocacy abilities can become a barrier to building this skill. Individuals who have had limited opportunities to make their own choices and have largely deferred to professionals, caregivers, and family members may struggle in expressing their preferences and need to go through a process of “unlearning” deferring to others in terms of choice making.

In addition, as a result of limited information and experiences, as well as misinformation, labels, and stereotypes, and a long-term history of low societal expectations, individuals often perceive their capabilities and opportunities as narrow and limited. Part of facilitating informed choice may be “undoing” previous information or helping an individual understand the misperceptions they are working under. It is critical that professionals be mindful of these challenges as they facilitate the informed choice process.

Simply put, making a well-informed choice is not something that will happen automatically. It is impacted by self-perception and by the skills and abilities a person has developed in choice making. However, with the right supports, individuals with even the most significant disabilities are capable of fully expressing their choices and preferences regarding how they spend their day-to-day lives. Providing ongoing opportunities for choice making, along with training on self-advocacy and self-determination, can assist in this regard.

Informed choice as an evolutionary process

If an individual has never envisioned themselves in the general workforce, it can be difficult for them to make that leap, without going through various steps akin to the Prochaska stages of behavioral change: precontemplation, contemplation, preparation, action, and maintenance. Activities can be undertaken over time that introduce the individual to the world of work (such as job tours and informational interviews) to help them envision themselves working in the community. This in turn prepares them to understand the possibilities and benefits of working, and then engage in a career planning process and job search plan, resulting in successful employment.

Informed choice as an ongoing habit

Informed choice should not be used just to decide if an individual wants to work in the general workforce. It can and should be used consistently, guiding the decision-making process in terms of what type of jobs to explore and apply to, management of benefits, how the individual will get to work, when to consider changing jobs, and other aspects related to employment and day-to-day lives in general.

Informed choice is for everyone

Informed choice is a natural part of everyone's adult life. Very few individuals, with or without a disability, make a decision without being informed on the options and potential consequences of their choices. To not allow this for persons with disabilities limits their ability to govern their own lives. Combining an informed choice philosophy with the strategies outlined in this guide will ensure that individuals with disabilities are making truly informed choices about their jobs, careers, and lives.

“Presume competence. And what we mean by presuming competence is when you meet a person with a disability you assume they are capable. Don't assume that someone can or can't do things but make sure they tell you what they need for accommodations and give them the chance to be in the driver's seat.”

-Max Barrows, Green Mountain Self-Advocates

Why Informed Choice Matters

It's the right thing: Informed choice is central to self-determination, self-advocacy, and person-centered planning, which are core tenets of best practices in services and civil rights for people with disabilities. Everyone has the right to self-determination and maximum decision making in how they live. Informed choice ensures that individuals with disabilities get to exercise those rights.

The law requires it:

- ▶ The U.S. Department of Justice (DOJ), in its guidance on implementation of the U.S. Supreme Court's Olmstead decision, has clearly indicated that simply asking individuals their preferences regarding where they want to live and spend their days is insufficient, DOJ has outlined specific steps that are required for ensuring informed choice in publicly funded services.
- ▶ Aligned with Olmstead, the Centers for Medicare and Medicaid Services has stated that individuals must have the opportunity to exercise informed choice regarding Home and Community Based Services funded by Medicaid (the funding source for most long-term services for people with disabilities).
- ▶ Under the federal Workforce Innovation and Opportunity Act (WIOA), state vocational rehabilitation agency services must be provided in a way that allows the individual to exercise informed choice.
- ▶ Section 511 of WIOA, which places limitations on payment of subminimum wages, requires that individuals receive career counseling that helps them explore and consider competitive integrated employment, and that this be done in a way that facilitates informed choice and independent decision-making.

The Process for Ensuring Informed Choice Regarding Employment

Informed choice requires a systematic, structured, and comprehensive process. To make a truly informed choice, people need to have varied experiences and good information. This includes extensive job exploration and discovery to ensure the individual's choices and preferences are fully understood, and all barriers to employment are identified and addressed. Staff play a critical role in effectively facilitating the process.

Steps for informed choice

The following is a step-by-step process for informed choice, based on best practices and guidance from the U.S. Department of Justice. This should not be considered wholly separate from other service processes, and ideally will be integrated within person-centered planning, career exploration, and discovery.

1. **Provide information about the benefits of working in integrated settings.** Examples include increased wages, economic self-sufficiency, and discretionary income; increased independence; opportunities to develop new skills and perform work that reflects personal interests; opportunities to build confidence, and a sense of fulfillment and accomplishment; opportunities to build new relationships and friendships; and greater control over how the person spends their day.
2. **Facilitate visits or other experiences in employment settings.** These can include situational assessments (short-term job tryouts, job sampling), informational interviews, job shadowing, job tours, etc. Use a variety of settings that reflect a diversity of potential employment opportunities, based on a person-centered approach that identifies the person's interests and what is important to them.
3. **Peer-to-peer discussions:** These discussions can involve individuals with disabilities meeting with peers who are working successfully in integrated employment, and/or families meeting with other families whose members are thriving in the workplace. Facilitate these discussions to promote dialogue regarding the successes experienced in community employment, the processes for achieving that success, and concerns/challenges that have been encountered and addressed.

4. **Identify and address any concerns or objections raised by the individual or relevant decision maker** (e.g., parent, guardian, case manager): Concerns and objections should not be viewed as insurmountable barriers to employment, but rather as issues to be addressed and resolved. See table on page 6 regarding common concerns and objections and how to address them.
5. **Regularly revisit a decision not to work in the community:** Informed choice is not a "one and done" process. If an individual is hesitant to consider working in the general workforce, low-risk steps can be taken to introduce them to the possibilities of employment and address any concerns (e.g., talking to peers who are working, viewing videos of individuals who are successfully employed, touring employment sites, visiting an American Job Center). During this exploratory process, the decision not to work in the community should be revisited periodically to see if the individual has changed their mind.

Documentation of informed choice

Fully document the process undertaken for informed choice for an individual, including the planned steps to address concerns or objections that have been raised, which can be reviewed at a later date. This documentation helps ensure the integrity of the informed choice process, and will also provide documentation for any type of review regarding whether an individual's right to informed choice has been fully respected and enforced. It is suggested that a standard format be used for documentation. The resource section at the end of this publication contains links to examples.

The role of *everyone* in informed choice

When it comes to informed choice, a variety of individuals are likely to be involved, including family members/guardians, funding source representatives, and support professionals. Support professionals not only include day program and employment services staff, but residential staff, mental health counselors, educators, and school personnel. All of these professionals should be fully supportive of informed choice in terms of both philosophy and practice. This includes sharing pertinent information to help the individual discover possibilities, and identifying and assisting with avenues for career exploration.

Staff roles: neutral or advocate for employment?

Most adults will work for much of their lifetime, and Employment First policies reinforce this societal expectation. Support professionals should never make a decision on behalf of an individual. However, staff are working within systems and programs where employment in the general workforce is the preferred outcome. Therefore, it is reasonable for staff to help the person understand their choices and options, advocate that they fully consider employment in the community, and ensure that all necessary steps be taken to maximize employment success. This includes staff emphasizing the benefits of working in the community, facilitating processes to ensure that an individual has given full consideration to employment options, and addressing objections and concerns regarding working in the community.

The role of family members

Family members are not necessarily going to be neutral in their approach to informed choice, and may have strong (and influential) views of whether or not their family member should work in the community. When working with family members, professionals should present the informed choice process as an opportunity to explore options in a low-risk and thoughtful way. Remind everyone that the process is centered on the person to whom the decisions apply, and is based on their wants and preferences.

Engage and inform the family about each step in the process. Acknowledge that choices the individual makes about work may have an impact on family members. Should an individual choose to pursue employment, working with family members as part of the career planning and discovery process will be important.

Statements that can help and hinder informed choice

The following statements can help facilitate a discussion regarding informed choice:

- ▶ *“What type of things are you interested in?”*
- ▶ *“Tell me more about why you’re interested in that.”*
- ▶ *“Why is that important to you?”*
- ▶ *“How would you go about learning more about that?”*
- ▶ *“What interests you about working in the community?”*
- ▶ *“What do you know about working in the community?”*

- ▶ *“What concerns you about working in the community?”*
- ▶ *“What did you like about that experience? What didn’t you like?”*
- ▶ *“Let’s go visit some workplaces and see what you find interesting.”*

Professionals can also sometimes subtly and inadvertently make statements that are at odds with informed choice. The following kinds of statements should be avoided:

- ▶ *“I really think you should do X.”*
- ▶ *“I think the best type of job for you is X.”*
- ▶ *“You don’t really want to do that, do you?”*
- ▶ *“I don’t think you would be good at that.”*
- ▶ *“What do you want to do that for?”*
- ▶ *“You’re happy at the sheltered workshop, aren’t you?”*
- ▶ *“Remember, you weren’t good at that.”*
- ▶ *“You’re not ready for work.”*

Choosing options that are less preferred

Discussions regarding employment and day services for individuals with disabilities will sometimes revolve around the rights of individuals to choose service options that may not be the generally preferred option in terms of publicly funded services, such as sheltered work, or a non-work day program. Individuals certainly have the right to choose such options if they are available. However, it is essential that they have the tools and information to make such a choice in a way that truly considers all possible options—and that the ultimate decision be reflective of the person’s preferences. It is also a decision that should be revisited in the future to determine if the individual has become interested in exploring employment in the community.

Informed choice does not happen automatically. It takes practice to become habit. And it requires a culture that encourages individuals to make their own decisions about what they think is best.

Responding to Common Objections to Employment

Concern/Objection	Response
I'll mess up my benefits and lose my medical coverage.	There are ways to maintain critical benefits and still go to work. Connect the individual with a benefits planner (Work Incentives Planning and Assistance, etc.), and provide information on online benefits calculators (e.g., DB101).
I'm worried about my safety working in the community.	Generally people with disabilities are safe in the community. Ask if they have experienced safety problems in the past. Note the safety track record for other individuals who are working. Identify specific safety concerns in a planning meeting, and strategies for addressing them (for example, working with the employer on safety issues, practicing using a cell phone to call for help, asking a bus driver for assistance, etc.).
I'll miss my friends in the workshop or day program.	Discuss how all friends are made over time and new ones can be made. Find options that will allow new interactions with current friends. Make sure potential jobs are a good fit socially for the individual.
It sounds scary. The workshop/day program is all I know.	Use a person-centered approach to discuss interests they can explore, and provide job tryout options before conducting a job search. Hold meetings with peers/mentors who have had success in community employment. Point out examples in the individual's life when they've made changes that may have been scary/uncomfortable at first, but they liked in the end.
How do I know the job will last? What if I lose it, or don't like it?	There are no guarantees, but there are steps that can be taken to maximize success. Discuss the variety of jobs available in the local area and set up informational interviews with employers to create awareness of options. Discuss how the job development process will work, how job supports will be provided, and how re-placement will occur if needed. Provide examples of individual success, and connect with peers who have been successful. Provide agency statistics on both placement and retention rates.
I'm scared of feeling alone.	Stress the steps that will be taken via the planning and discovery process so the individual finds a job that is a good match for them socially, and that promotes interactions with others and full inclusion. Discuss how provider staff will work with the individual and employer to facilitate full social inclusion in the new workplace.
I don't even know what jobs are out there.	Conduct discovery activities such as job shadowing, short-term job tryouts, and volunteering.
My family and friends don't think I should work.	Identify and address the concerns family and friends may have through processes such as person-centered planning. Remind the person that while family and friends mean well, it is ultimately the individual's decision on whether and where they go to work.
I worked in the community before, and it was terrible.	Remind the individual that lots of people try different jobs (and sometimes fail) before they find the right one. Explore why the previous work experience went poorly, and how those issues can be addressed via a better job match and support. Find avenues to experience new work situations to build confidence (volunteering, job shadowing, and job tryouts) before pursuing a final job goal.
It's my choice to stay in the sheltered workshop or day program.	Validate that the individual has the right to stay in a sheltered workshop or day program (assuming funding and eligibility for these services continues). However, emphasize that the individual is capable of doing other things, and encourage them to take even a few steps to at least consider other options. Also, emphasize that working in the community provides a wide range of choices and options.

Informed choice and transition

Ideally, people with disabilities will practice choice making from an early age. As transition planning begins during the teen years, opportunities for choice making should be expanded and begin to include decisions regarding employment and career options, using the philosophy of and processes for informed choice.

As the young person explores employment, provide opportunities for self-reflection by asking: What types of careers are you interested in looking at and why? What did you learn from a specific work experience? What did an experience teach you in terms of employment interests? How are you going to use this information to further explore job and career interests?

Responding to Common Objections Regarding Community Employment

In discussing community employment, individuals may express concerns or objections (see chart on page 6). It is important to be prepared with responses for these. The goal is not to downplay the concerns or objections, but to understand them and identify how you might support the individual to address them.

First, acknowledge the concern or objection. Ask follow-up questions if you need more information. Then engage the individual in identifying potential strategies to address the concern. Keep in mind that many individuals and their families have been part of the service system for a long time, and solutions have often been promised that may not have resolved their concerns. Their past experiences will influence their response to new opportunities.

You also do not have to have all the answers. Sometimes your best response may be to commit to work on an issue or potential barrier to employment with the individual, and when appropriate their family.

The Role of Guardianship in Informed Choice

Even if an individual with a disability is not their own legal guardian, they still have the right to informed choice. Per The Arc of the United States, all individuals “should be afforded opportunities to participate to the maximum extent possible in making and executing decisions about themselves. Guardians should engage individuals in the decision-making process, ensuring that their preferences and desires are known, considered, and achieved to the fullest extent possible.”

Consider these guidelines when dealing with guardianship issues:

- ▶ **Determine the parameters of the guardianship**—i.e., what specific issues the guardian has responsibility for, which can vary from individual to individual. In some cases, it may be legally necessary to involve the guardian in issues regarding employment, but in other cases that might not be required.
- ▶ **Learn what type and level of relationship the guardian has with the individual.** If the guardian is a family member, they have an emotional attachment and are potentially involved in day-to-day decisions. A state-appointed guardian will have a professional relationship and may have more limited contact with the individual.
- ▶ **As appropriate, involve the guardian, and advocate for their support of the informed choice process.** As explained by The Arc, it is the role of the guardian to know and understand the individual’s needs and wishes and act in accordance with them whenever possible, and whenever any action will not negatively affect the individual’s health, safety, financial security, and other welfare. If the guardian opposes the choices that an individual is making in terms of employment, assuming they have the right to do so, determine their reasons for opposition, and work to address the issues.

The National Guardianship Association Standards of Practice can be helpful regarding the appropriate role of a guardian in terms of informed choice. Among these standards are:

1. The guardian shall identify and advocate for the person’s goals, needs, and preferences.
2. The guardian shall attempt to maximize the self-reliance and independence of the person.
3. The guardian shall encourage the person to participate, to the maximum extent of the person’s abilities, in all decisions that affect him or her, to act on his or her own behalf in all matters in which the person is able to do so.
4. The guardian shall make and implement a plan that seeks to fulfill the person’s goals, needs, and preferences. The plan shall emphasize the person’s strengths, skills, and abilities to the fullest extent in order to favor the least restrictive setting.
5. The guardian shall wherever possible, seek to ensure that the person leads the planning process; and at a minimum to ensure that the person participates in the process.

Programmatic Considerations Regarding Informed Choice

The following questions can guide programs and services in maximizing informed choice:

- How do you ensure a culture and atmosphere that supports informed choice, and avoids individuals deferring to staff or family members?
- Who should participate in the informed choice discussions and process?
- How will individuals with communication and other support needs be supported in a way that allows them to fully participate, ensures their right to informed choice, and avoids professional interference?
- How will opportunities in the community be explored? How do you ensure exposure to a variety of settings and jobs that are of possible interest?
- What will you do if the individual seems hesitant to consider going to work in the community?
- What should you do when someone other than the individual being supported pushes a decision?
- What do you have in place to document the informed choice process?
- What process do you have in place for review of and periodically revisiting a decision not to work in the community?

Professional skills to assist with the informed choice process. Just as individuals need to learn and practice informed choice, so do service providers and professionals who are facilitating the process. The following is a suggested list of staff competencies:

1. Skilled listening
2. Cultural awareness and competency regarding choice-making
3. Influence and impact of staff values and personal values on choice-making
4. Facilitating empowerment of individuals to direct the process
5. Managing conflict

Resources

Employment First - The Role of Informed Choice:

PowerPoint presentation by Dr. Joan Kester of George Washington University that outlines various issues regarding informed choice in the context of Employment First. www.slideserve.com/quasar/employment-first-the-role-of-informed-choice

Holding Engaging Conversations about Work - Toolkit to Support Informed Choice in Employment, Minnesota Department of Human Services:

Toolkit to help support professionals guide people with disabilities to consider employment as an option and plan for work, developed by the Minnesota Departments of Education, Employment and Economic Development, and Human Services. https://mn.db101.org/documents/Informed-Choice-Toolkit-Revised_1.12.18.pdf

New Jersey Department of Human Services, Division of Developmental Disabilities:

New Jersey's requirements for full consideration of employment in service planning aligned with the state's Employment First Policy, provide an example of specific policies and procedures to ensure informed choice.

- **Policy:** *Supports Program Policies and Procedures Manual* – Policy regarding consideration of employment options as part of service planning - see pp. 40-44. www.nj.gov/humanservices/ddd/documents/supports-program-policy-manual.pdf
- **Form:** *Pathway to Employment* – Step by step guide to ensure full consideration of employment aligned with the state's Employment First policy and informed choice. Available via link at: <http://njsupportingcommunitylives.org/support-coordination/documents/>

Virginia Department for Aging and Rehabilitative Services - Supporting Informed Choices About Employment.

Guide for ensuring informed choice regarding employment - www.vadars.org/essp/downloads/Informed%20Choice%20and%20Employment-%20Sept%202017.pdf

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