

Individual Choice: Training Guide

Why Choice Matters

- **Legal and ethical right** for adults.
 - Promotes **community integration and independence**.
 - Research shows:
 - People prefer situations where they can choose.
 - Choice increases participation and may reduce problem behaviors.
 - Control over aversive situations reduces stress.
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Challenges in Promoting Choice

- Individuals may not know how to make choices.
 - Risk of poor decisions or excessive freedom.
 - Skill deficits can increase dependency and societal costs.
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Strategies for Supporting Choice

1. Assess Preferences

- Use interviews, observations, and tools like “And Here’s What I Want.”
- Track likes/dislikes over time.

2. Teach Choice-Making

- Use visual, auditory, or tactile communication tools.
- Reinforce “yes” and “no” responses.
- Teach natural consequences and problem-solving.

3. Integrate Choice into Daily Life

- Embed choices in schedules, behavior support plans, and participation plans.
- Offer choices in materials, activities, people, locations, and timing.

4. Family and Group Decision-Making

- Use structured family conferences with clear rules.
- Encourage collaborative problem-solving.

Conclusion

Empowering individuals with developmental disabilities to make choices enhances their autonomy, dignity, and quality of life. The presentation calls for a cultural shift toward **“Choose Choice!”**

Individual Rights: Training Guide

Purpose and Foundations of Individual Rights

- People with developmental disabilities have the **same rights as all citizens**.
 - Rights are rooted in the **U.S. Declaration of Independence**:
 - **Created equal**: All people have equal value and worth.
 - **Unalienable rights**: Rights cannot be taken away or denied.
 - **Pursuit of happiness**: Everyone has the right to make choices that lead to personal fulfillment.
 - Historically, rights have not always been equally applied — people with disabilities were often institutionalized, denied education and community access, subjected to abuse and neglect.
 - The disability rights movement, including the **ADA (1991)**, help **fight for recognition and equality**, expanded rights and inclusion, shaping the way services are delivered today.
 - Rights are described as “**non-physical things that can’t be taken away.**”
 - Rights are learned over time through **experience, opportunity, and support**.
 - Staff play a critical role in **promoting and protecting rights** in every interaction.
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Everyday Lives Values In Action

- Developed in 1991 by asking individuals and families: “**What is important to you?**”
 - Core values shaping service delivery today:
 - **Freedom**: Same rights as others, fully usable and respected.
 - **Control**: Over all areas of life.
 - **Choice**: About everything in life, with support to explore options.
 - **Communication**: Everyone must have an effective way to express themselves.
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Key Concepts in Practice

Choice and Decision-Making

- Includes both **big decisions** (career, relationships, living arrangements) and **everyday choices** (food, activities, what to wear).

- Informed decisions are based on:
 - Personal experience
 - Trusted advice
 - Exploration and trial
 - Understanding risks and benefits
- Staff must:
 - Ask if support is wanted before offering advice.
 - Recognize and challenge personal assumptions.
 - Respect the individual's pace and preferences.

Communication as a Right

- Communication is constant and essential for:
 - Expressing feelings
 - Making choices
 - Staying safe
 - Building relationships
- People communicate through:
 - Words, gestures, sounds, facial expressions, behaviors
 - Technology (AAC devices, text, email)
- **Behavior is communication**, especially for non-verbal individuals.

Dignity of Risk

- Trying new things involves risk—but also lends to growth and fulfillment.
- Staff must balance:
 - Respect for autonomy
 - Responsibility for health, safety, and emotional well-being

Speaking Up and Being Heard

- Individuals have the right to:
 - Change their minds
 - Disagree or complain

- Refuse services or decisions
 - Staff must respond respectfully and use feedback to improve support.
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Self-Advocates' Insights

Qualities of good support people:

- Listen with respect, be alert for non-verbal communication / behaviors
 - Be patient, give time to get it out
 - Ask yes/no questions or rephrase to better understand
 - Collaborate with those who know the individual best.
 - Use technology and tools that match the person's needs.
 - Follow through and show up on their words
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Rights in Community and Relationships

- Being part of a community means **being known, valued, and missed**.
 - Community connections enhance **safety, dignity, and belonging**.
 - Relationships deepen support and advocacy.
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Legal Protections

- **Federal:** CMS Final Rule (2014) ensures rights to privacy, dignity, respect, and freedom from coercion.
 - **State (PA):** 55 PA Code Chapter 6100 supports full community participation and independence.
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Staff Responsibilities and Everyday Practice

- Everyone—from DSPs to admin staff—has a role in promoting rights.
- Use respectful language and actions.
- Promote:
 - **Privacy:** Knock before entering, protect personal info.
 - **Inclusion:** Talk with people, not about them.

- **Dignity:** Focus on strengths, not limitations.
 - Support is **active**, not passive:
 - Listen and respond
 - Offer experiences that build confidence
 - Model respect in every interaction
 - Supporters should ask: “How would I want to be treated?”
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Reflection: Rights We All Share

- Respect, dignity, privacy, and choice are **universal rights**.
 - Rights are not just for people with disabilities—they’re **human rights**.
 - “Give me options and I will choose.”
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Final Message

“I did then what I knew how to do. Now that I know better, I do better.” — Maya Angelou

References:

Pennsylvania Department of Human Services, Office of Developmental Programs.
Individual Rights Webcast #1 – Rights: What Do We Mean?, Individual Rights Webcast #2 – Choice and Decision-Making.
Individual Rights Webcast #3 – The Right to Communicate. Individual Rights Webcast #4 – When We Know More, We Can Do Better. The Columbus Organization, 2018. MyODP, www.myodp.org.

Person Centered Practices: Training Guide

Core Themes of Person-Centered Practices

Defining of Person-Centered

- Seeing individuals as **unique people**, not defined by their disabilities.
 - Honoring their **desires, interests, values, relationships, and lifestyles**.
 - Involving individuals in **decision-making** and respecting their choices.
 - Emphasized by the phrase: **“Nothing about me, without me.”**
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ODP Mission and Vision

- **Mission:** Support Pennsylvanians with developmental disabilities to achieve **independence, choice, and opportunity**.
 - **Vision:** Create a system of services that are **flexible, innovative, and person-centered**.
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Values from Everyday Lives: Values in Action

This ODP publication outlines values important to people with developmental disabilities:

- **Connection** to community
 - **Responsibility** and commitment
 - **Communication** that is understood and respected
 - **Success** in personal interests
 - **Employment** and **contribution**
 - **Individuality, relationships, and partnership**
 - **Stability, health and safety, quality services, and advocacy**
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Ask yourself....

- What are my most **positive qualities**?

- What makes a **good day**?
- Are there certain people and places that make me feel **valued and welcomed**?
- Do I have any **relationships** that support me?

These reflections help us understand the **importance of recognizing and supporting similar values** in the people we serve.

Balancing Meaning and Safety

- A good life includes both **meaningful experiences** and **health/safety**.
 - We are encouraged to help individuals **maintain this balance**, recognizing that both aspects are essential to well-being.
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Importance of Relationships

- Relationships provide **belonging, safety, and support**.
 - Being person-centered means **valuing and fostering relationships** that help individuals thrive.
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Language Matters: People First Language

- Avoid defining people by their disabilities (e.g., “diabetic” or “wheelchair-bound”).
 - Use respectful language that emphasizes the **person first** (e.g., “person with diabetes” or “uses a wheelchair”).
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Choice as a Fundamental Right

- Making choices is a **basic human right** and essential to personal identity and independence.
- People make thousands of choices daily—some impulsive, some deliberate.
- Individuals with developmental disabilities deserve the same opportunities to make choices.

ODP's Commitment to Choice

- Embedded in ODP's **mission and vision** and the **Everyday Lives** framework.
 - Annual **IM4Q (Independent Monitoring for Quality)** surveys measure how much choice individuals experience (e.g., voting, living arrangements, daily activities).
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Types of Choices

- **Impulsive:** quick decisions without much thought.
 - **Delegated:** letting someone else decide.
 - **Avoided:** choosing not to choose.
 - **Deliberate:** weighing options and consequences.
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Benefits of Choice

Research shows that having choices:

- Increases **participation**
 - Improves **performance**
 - Reduces **problem behaviors**
 - Enhances **tolerance** for unpleasant situations
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Informed Choice

- Requires **experience, information, and support**.
- Supporters must help individuals understand:
 - Available options
 - Potential consequences
 - Personal preferences

Example: Helping someone choose a snack by narrowing options based on allergies and preferences.

Supported Decision-Making

- A process where individuals receive help to make their own decisions.
- Supporters ask questions, provide information, and help weigh pros and cons—without making the decision for the person.

Example: A sister helping her brother choose an apartment by guiding him through financial and lifestyle considerations.

Building Experience

- Many individuals with disabilities lack experience in making choices.
- Supporters should:
 - Offer **limited, manageable options**
 - Encourage **trying new things**
 - Observe **verbal and non-verbal cues** to understand preferences

Example: Derek tries avocado for the first time before deciding whether to include it in his meal.

Balancing Choice and Risk

- Choice often involves **risk**—but risk should not prevent choice.
- Supporters must help individuals:
 - Understand risks
 - Learn from mistakes
 - Find **safe alternatives** that still honor the person's preferences

Example: Josh wants to visit the barbershop alone. His team supports this by teaching him to send a text when ready to be picked up.

Making Unpleasant Choices More Bearable

- Pairing unpleasant tasks (e.g., medical appointments) with enjoyable activities (e.g., visiting animals) can help individuals make better choices.

Example: Ashley dislikes doctor visits but enjoys animals. Her team plans animal-related activities after appointments to motivate her.

Three Types of Communication

- **Verbal:** Spoken words (only 7% of communication)
- **Para-verbal:** Tone, rate of speech, pauses (38%)
- **Non-verbal:** Facial expressions, gestures, posture, sounds (55%)

Insight: Most communication is non-verbal or para-verbal, making it essential to observe behavior and context.

Behavior as Communication

- People express wants, needs, and feelings through **actions**, especially when they don't use words.
- **Mismatch between words and actions** can indicate deeper issues (e.g., discomfort, trauma, lack of trust).

Example: Someone says they love biking but avoids it—maybe they prefer tinkering with bikes or dislike the seat.

Trust and Relationships

- Communication is shaped by **trust** and **relationship history**.
 - People may not express true preferences until they feel **safe and respected**.
 - Past trauma or neglect can lead to **mistrust**, making communication more complex.
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Medical and Emotional Influences

- Illness, grief, or psychological distress can affect communication.
 - A person may decline an activity they usually enjoy due to **temporary emotional or physical reasons**.
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Understanding Communication to Guide Support

- Listening to both **words and actions** helps tailor **person-centered supports**.
 - Supports should promote **meaningful experiences** while ensuring **health and safety**.
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? Respectful Guessing

- When behavior is unclear, use known information to make a **best guess**.
 - If the guess is correct, trust is built. If not, the effort still shows respect and promotes understanding.
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How New Staff Can Engage

- Even without direct support roles, staff can:
 - **Greet individuals**
 - **Acknowledge non-verbal cues**
 - **Ask for help understanding communication**
 - These small actions build **trust and connection**.
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Assume Competence

- Never assume someone has nothing to say because they don't use words.
- Recognize and value **all efforts to communicate**.
- Respect leads to **relationships, trust, and better support outcomes**.

Defining Community

- Community is no longer just a **physical place** (neighborhood, school, workplace).
 - It also includes **shared interests, cultural identity**, and **online communities**.
 - True community means **connection, relationships**, and **belonging**.
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Historical Context

- Historically, people with disabilities were **institutionalized** and excluded from society.
 - The shift in the 1970s–80s brought people **back into their communities**, but many remained **isolated** or **unknown**.
 - Inclusion means **being known, valued**, and **connected**.
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Six Key Factors of Community Inclusion

Presence

- More than just being physically present—it's about **active participation** in community life.
- Examples: joining a gym, volunteering, being recognized by name at local businesses.

Choice

- Inclusion expands **opportunities** and **choices**.
- New experiences lead to new relationships, which in turn lead to more choices—a **positive cycle**.

Competence

- Competence grows through **experience** and **recognition**.
- When people are seen as capable, they're given more opportunities.
- Example: Kristen's journey from being present to being active in her community through work, volunteering, and social activities.

Respect and Valued Roles

- Use **People First Language** to show respect (e.g., “Lori loves to sing” vs. “wheelchair-bound”).
- Language shapes attitudes, which shape actions.
- Everyone deserves to be seen as a **whole person**, not defined by disability.

Participation

- True participation means being **involved, missed when absent**, and having **shared experiences**.
- Pennsylvania’s **Community Participation Supports (CPS)** program promotes employment and meaningful engagement.

Belonging

- Belonging means being **known, missed**, and **looked after**.
 - Example: Tim’s neighbors check on him when his parents are late—he’s part of the community.
 - Belonging fosters **safety, connection**, and **purpose**.
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Relationships Are Fundamental

- Inspired by John Donne’s quote: “No man is an island.”
 - Relationships are a **basic human need**—they give life **joy, meaning, and stability**.
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Mapping Relationships

Participants are asked to list people in three categories:

- **Friends and family**
- **People known in the community**
- **People paid to support them**

This exercise helps visualize the **balance and closeness** of relationships.

Person-Centered Relationship Mapping

- A **relationship map** places people closer or farther from the center based on emotional closeness.
 - Individuals decide who is important to them.
 - Relationships **change over time**, and maps evolve accordingly.
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Contrast in Relationship Balance

- Most people have more **natural relationships** than paid ones.
 - For individuals with developmental disabilities, the **balance may be reversed**, with more paid support relationships.
 - This can lead to **isolation**, even when care is respectful and professional.
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The Value of Deep Relationships

- Deep relationships offer:
 - **Shared history**
 - **Emotional support**
 - **Understanding of personal values and traditions**
 - **Advocacy and trust**
 - **Stability during life changes**

Example: Mac, known as “The Mayor of 13th Street,” was saved by his community’s concern when he fell ill.

Relationships Promote Safety

- People who are **known and cared for** are more likely to be protected from:
 - Physical harm
 - Exploitation
 - Abuse

Fostering Relationships: Practical Strategies

💖 How Relationships Form

- Repeated interactions in shared spaces (e.g., school, church, neighborhood)
 - Discovery of **shared interests**
 - **Invitations** to connect outside the initial setting
 - **Mutual appreciation and commitment**
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⚙️ Supporting Relationship Maintenance

- Help individuals **stay connected**:
 - Transportation
 - Communication tools (e.g., texting, assistive tech)
 - Encouragement to engage
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🔗 Community Connection Examples

- Harry was missed at McDonald's.
 - Carol's knitting group valued her humor.
 - Lee was invited to coach Paralympic athletes.
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✅ Core Message

Being person-centered is not a task or a checklist—it's a **way of thinking and acting** every day. It involves:

- Supporting **choice**
- Understanding **communication**
- Promoting **community inclusion**
- Fostering **relationships**

These elements are **interconnected** and must be practiced **consistently** across all roles in an organization.

We are encouraged to consider:

- **Where** in their job they can support person-centered practices.
- **What** they can do today or tomorrow to make a difference.
- **How** they will help individuals live their **Everyday Life**.

Additional information on Person Centered Practices can be found at the link below

<https://www.myodp.org/course/view.php?id=2382>

Relationships & Boundaries: Training Guide

What Are Relationships?

- Defined as ongoing, committed associations between people that influence thoughts, feelings, and actions.
- Considered a **basic psychological need** (Maslow's Hierarchy: Love/Belonging).

Why Relationships Matter

- People with disabilities express a desire for:
 - Companionship
 - Lasting relationships
 - Safety and choice
 - Healthy decision-making
- Relationships contribute to:
 - Happiness
 - Stress reduction
 - Immune system support
 - Personal growth

Challenges for People with ID/A

- Loneliness and isolation
- Dependence on paid caregivers
- Stigma and ableism
- Limited time, privacy, transportation, finances, and tech access
- Caregivers may unintentionally control relationship-building



Everyday Lives Values

- Individuals should choose who is in their life
- Relationships desired by individuals should be respected and supported



What Makes Relationships Work

- Reciprocity
- Shared interests
- Frequent contact
- Hospitality and curiosity
- Willingness to try new things



Teaching Healthy Relationships

- Emphasize mutual respect, boundaries, and equality
- Teach:
 - Hygiene and appearance
 - Assertive communication
 - Consent and privacy
 - Healthy vs. unhealthy traits
 - Personal space



Strategies to Foster Relationships

- Use modeling and role-play
- Create opportunities for friendships
- Reinforce interpersonal skills
- Encourage community involvement and leisure
- Support self-advocacy and research participation.

Daily Support Strategies

- Help build positive identity
- Encourage giving and volunteering
- Meet individuals where they are
- Respect preferences and evolving needs
- Avoid imposing personal expectations

What Are Personal Boundaries?

- Limits and rules based on comfort levels.
- Can be physical, verbal, emotional, or situational.
- Exist even if not verbalized.
- Context matters—what's appropriate depends on the setting.

Boundaries and People with ID/A

- Individuals may struggle with understanding boundaries due to impairments in conceptual, social, and practical skills.
- May have learned compliance over assertiveness.
- Teaching boundaries can improve mental health and reduce challenging behaviors.

Categories of Boundaries

1. **Emotional** – Sharing feelings, expressing discomfort.
2. **Physical** – Personal space, type and amount of touch.
3. **Sexual** – Consent, appropriate partners and settings.
4. **Workplace** – Saying no, maintaining professionalism.
5. **Material** – Respecting property, saying no to lending.
6. **Time** – Managing time, saying no when overwhelmed.

Boundary Styles

- **Rigid** – Avoids closeness, overly protective.
- **Porous** – Overshares, fears rejection, struggles to say no.
- **Healthy** – Communicates needs, respects self and others, maintains values.

Benefits of Healthy Boundaries

- Reduces risk of abuse
- Improves communication and relationships
- Builds trust
- Supports self-care and emotional well-being

Teaching Boundaries to People with ID/A

- Discuss types of relationships and public vs. private behavior
- Teach appropriate vs. inappropriate touch
- Encourage assertiveness

Strategies for Teaching

- **Model** healthy boundaries
- Practice with **roleplay**
- Observe and discuss behaviors in media
- Reinforce concepts regularly

Tips for Modeling and Supporting

- Avoid oversharing and ask permission before touching
- Validate emotional needs
- Encourage speaking up using confident body language and tone

Community Inclusion: Helping vs. Hovering

Purpose

To explore the difference between **supporting inclusion** and **over-supporting (hovering)**, and to provide strategies for fostering meaningful community participation for individuals with disabilities.

Key Concepts

1. Inclusion vs. Presence

- **Inclusion** means being a valued, active member of the community—not just physically present.
- True inclusion involves **relationships, contributions, and natural supports**.
- **Hovering** can unintentionally hinder independence and social growth.

2. Historical Context

- The shift from institutionalization to community-based support began over 50 years ago.
- The **Americans with Disabilities Act (ADA)** and the **1999 Supreme Court Olmstead decision** emphasized community integration.

3. Building Blocks of Inclusion

- **Physical:** Being in community spaces.
 - **Social:** Forming relationships.
 - **Instructional:** Learning skills for participation.
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What Inclusion Is and Isn't

Inclusion is:

- Meaningful relationships
- Community contribution
- Support that fosters independence

Inclusion is not:

- Just being in public places
 - Following a checklist
 - Creating sub-groups within the community
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Challenges Identified

- Many individuals with Autism Spectrum Disorder (ASD) experience **social isolation**:
 - 24% had no social contact.
 - 1 in 3 had no community participation.
 - Isolation rates were 3–4 times higher than other disability groups.
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Helping vs. Hovering

Helping involves:

- Teaching skills
- Encouraging independence
- Supporting choice and self-direction
- Example: explaining several food options at a restaurant, allowing the individual to choose between options, and encouraging them to communicate their choice to the wait staff

Hovering includes:

- Making decisions for the person
 - Speaking on their behalf
 - Over-involvement in social interactions
 - Example: ordering the chicken tenders for the individual because you know they will eat them and not offering input from the individual or a social exchange with the wait staff
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Strategies for Inclusion

- Identify strengths, interests, and social networks.
 - Expand the “geographies” of where individuals spend time.
 - Promote natural supports and regular participation in community activities.
 - Teach choice-making and opportunities to practice social skills.
 - Encourage valued social roles (e.g., employee, neighbor, volunteer).
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Valued Social Roles

These roles enhance:

- Opportunities
- Relationships
- Self-esteem
- Belonging
- Control

Support staff should focus on **image enhancement** (appearance, setting, language) and **competency development** (skills needed for roles) to allow individuals opportunities for meaningful community inclusion and belonging.