



**Becoming a Professional
Individual Provider (IP)**

Student Manual

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Referral & Workforce
Resource Center

Your Future is Our Priority

Acknowledgements

Training to prepare new workers for in-home care is the result of many people across Washington who share a common vision to improve the individual provider workforce. The input and expertise we have received comes from all corners of the state: from workers, employers and their families, educators, policy-makers, and concerned citizens. Without the extensive network of people who willingly shared their thoughts, hopes and dreams, this manual and a host of other materials we've developed would not be possible.

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About the Training

This *Becoming a Professional Individual Provider* course is three hours of training, which is designed to be completed in one continuous session.

Key Words

Each section of this course will begin with “Key Words” in which words that are used in the section will be defined or described.

For example, in this section the word **individual** is defined as “How this training refers to individuals receiving publicly-funded in-home services. It will remind you to treat each person you support as an individual with unique interests, abilities, preferences, and needs.”

You may use the words “consumers” or “employers” or some other word when referring to people you support, but it would be beneficial to find out from your employer which term(s) they prefer. However, throughout this training, individuals receiving in-home services will be referred to as “individuals” or, in some instances, “people” or “person.”

Homework

There will be no written homework in this course.

Quizzes

At the end of each section of this course, you will have a short quiz. The quiz questions will be multiple choice. We will go over the answers together in class.

Student Participation

It is important to actively participate in all course activities. You will be building upon your knowledge through reflection (your own experiences, thoughts and perceptions) as well as learning from your colleagues through paired activities or small group exercises.

Word of Caution

Before we start this training, it is important to note that this training does not replace the professional advice of doctors, lawyers, and other experts. This training is based upon what are widely considered to be preferred practices. However, circumstances for each individual are unique and therefore require services and supports specifically designed to meet that individual's needs.

As preferences differ from person to person, it is expected that you will familiarize yourself with the preferences of your employer. It is possible that some practices with your employer will differ from preferred practices that you learn from this training. What should you do? Start by talking to your employer about these differences and the best course of action. And remember: never risk your safety or that of an individual, to do something for which you feel unqualified. It is always okay to ask for help.

The Individual Provider

OUTCOMES

When you finish this session, you will be able to:

- Define the term “developmental disability.”
- Define the term “functional disability.”
- Identify differences between functional and developmental disabilities.
- Identify the values of the Washington service system for individuals receiving in-home care.
- Demonstrate awareness of your own attitudes and beliefs about others and how those attitudes and beliefs may impact your work.
- Describe your general role in the Washington service system for individuals receiving in-home and self-directed care.
- Define “philosophy of independent living;” how it impacts your work.
- Identify ways to use ethics, observation, communication, decision making, and documentation in your work.
- Describe your role as a team member.
- Use “People First” language.
- Identify ways to determine how others would like to be treated.

KEYWORDS

Developmental Disability: A developmental disability begins before someone reaches 18 years of age; is something that goes on throughout a person’s life; is a substantial disability for the individual; and often means there is a need for some kind of assistance.

Functional Disability: Pain, weakness, stiffness or paralysis caused by sprain, stroke, traumatic brain injury, or due to congenital (a condition a person is born with) disability.

Individual Provider (IP): An IP works with and supports people with developmental disabilities, who are elderly and others who receive publicly-funded services where they live and work.

Individual: How this training refers to Individuals you will work for. It will remind you to treat each person you support as an individual with unique interests, abilities, preferences, and needs.

People First Language: Language that refers to the qualities of a person, not a person’s disabilities.

Platinum Rule: Treat others as they would like to be treated.

Professional Ethics: A set of standards to guide one’s professional behavior.

Values: Ideals that shape the quality of services and supports.

Introduction

W

hat is the reason for this Individual Provider (IP) training? There are two reasons, and they are connected to each other.

The first is to help you do the best job you can in supporting individuals to have a better quality of life. The second reason is this: when you do the best job you are able to do, your professional life

should be more rewarding, which should improve your quality of life. As an IP there is something valuable in this training, not only for the individuals you are working with, but for yourself personally. There is nothing better than a situation in which everyone wins! We will begin the training by getting to know each other and learning more about what the training will cover.

ACTIVITY

Getting to Know You

Directions: Pair up with someone in class. Take turns asking each other the following questions. Write your partner's answers below.

What is your name?

.....

Where do you work (or where have you worked recently)?

.....

What are three positive words that describe how you feel about the work you will do as an individual provider?

1

.....

2

.....

3

.....

Supporting a Better Quality of Life

So what does “quality of life” mean? It means different things to different people. Generally, people experience a good quality of life when they:

- Are able to make choices in their lives, and their choices are encouraged, supported, and respected.
- Have close, supportive relationships with friends and family.
- Live in a home that is comfortable for them and with people who know and care about them.
- Participate in activities they find enjoyable.
- Have access to health care and have the best possible health.
- Feel safe and are safe.
- Are treated with dignity and respect.
- Are generally satisfied with their lives.













ACTIVITY

Directions: Think about what “quality of life” means for you. Write down five things that are important in your life (things you think are necessary for you to have a good quality of life).

1. _____
2. _____
3. _____
4. _____
5. _____

Supporting a Better Quality of Life, *continued*

Now let's see what some people with developmental disabilities have to say about what quality of life means to them. In 2003, a number of individuals with developmental disabilities were asked, "What does quality of life mean to you? What things are important in your life (things that you think are necessary for you to have good quality of life)?" This is what they said:

- I choose my own friends 
- I do what I want on  weekends
- I spend my own  money
- I  cook whenever I want
- I  eat out
- I decide how to spend my own  free time
- I live where I want  to live
- I make my own  decisions
- I have the  freedom to work  when I want
- I work where I want to work 
- I can  go to college

SOURCE: Community Conversations with People with Developmental Disabilities in California. Published by California Department of Developmental Services at http://www.dds.cahwnet.gov/cac/pdf/CAC_ConversationswDD.pdf

Supporting a Better Quality of Life, *continued*

In many of the above areas, the individuals surveyed felt they were doing pretty well; however, individuals said they specifically wanted more choices in the area of relationships, personal care, and personal freedom.

Relationships

In the area of relationships, they wanted to spend more time with friends, see their families more often and at holidays, spend some time with boyfriends and girlfriends, and get married.

Personal Care

In the area of personal care they wanted better trained doctors and more of them, good healthy food available, and more recreational opportunities.

Personal Freedom

In the area of personal freedom, they wanted to spend more time in the community, to make their own decisions about when to go on a diet, to go on more vacations, and to be more a part of their communities.

People wanted to say some very specific things to the people who support them: that means you. They want to wear clean clothes; to decide on their own bedtime and not to have a schedule; to watch the television programs they like at the times they want; to see boyfriends and girlfriends when they want; and, to invite more visitors to come over to visit.¹

As we go through this training, listen, learn, and think about what individuals you will or currently support have to say about what is important to them and how you can apply what you learn in supporting the individuals you serve to lead quality lives.

¹ Excerpted and Adapted from Department of Developmental Service's Consumer Advisory Committee, *Community Conversations with People with Developmental Disabilities in California*.

The Individual Provider

A

N Individual Provider (IP) works with and supports individuals in the places they live and work. IPs perform their jobs in privately-owned homes, licensed homes, day programs, supported or independent living environments, or work sites. An IP has many important roles to play.

You are:

- A **PARTNER**, supporting individuals in leading independent lives and participating in and contributing to the community.
- A **TEACHER**, finding creative and fun ways to help individuals learn meaningful skills and providing them with information to make the best choices for themselves.
- An **AMBASSADOR** to the individual's community, encouraging others to support individuals you support as neighbors, friends, and co-workers.
- An **ADVOCATE**, supporting individuals in exercising their rights and responsibilities.
- A **SUPPORTER** seeking to understand the likes, dislikes, hopes, and dreams of individuals you support and cheering individuals on as they make progress toward their life goals.

All of the roles that you play have a common focus on supporting individuals to live the kind of life they hope and dream about. The IP is a Partner, Teacher, Ambassador, Advocate, and Supporter.

The IP is *not* a boss or one who orders people around and makes them do things they may or may not want to do. Likewise, the IP should *not* act like a parent to the people they support who are not their own child.

The job of the IP carries a great deal of responsibility, and it is easy to get these roles confused. Unlike a parent, legal guardian, or conservator, the IP who is not related to the person they support does not have the responsibility to make important life decisions for individuals they work for and with.

Instead, the individuals themselves, with the help of parents, legal guardians, families, or conservators, as appropriate, make decisions about their own lives.

Scenario: Role of the Individual Provider

Featuring



Jarred

A 23 year-old man



Mike

Jarred's individual
provider



Lois

Health club manager

Jarred is sitting on the front steps of his house. He looks dejected. Mike, his individual provider, asks Jason why he looks bummed out.

Jarred: "I got kicked out of the gym."

Mike: "Why?"

Jarred: "Some guys were calling me names."

Mike: "Why did they do that?"

Jarred: "I don't know."

Mike: "Which gym were you playing at? The one on Main Street?"

Jarred nod his head yes.

Mike: "I know that gym. I'm gonna call them and find out what's wrong."

Mike is inside the house on the phone. He calls Lois, the health club manager. Mike describes Jarred to Lois.

Lois: "Oh yeah, that slow guy."

Mike: "Well, ah, I was wondering why he was asked to leave the gym the other day. He says he was kicked out."

Lois: "He doesn't know how to play basketball properly so he gets fouled all the time. I figured I saved him from getting beat up."

Mike: "Maybe his basketball and social skills aren't the best, but Jarred really enjoys playing basketball. Is it okay for him to still come to the gym?"

Lois: "Maybe it's just better if he plays at the park."

Mike: “Well, we do go to the park and he enjoys that. But the gym is much better for him.”

Lois: “Okay, okay. I get it. Don’t make problems for me. Since he’s special, I’ll make a deal with you. I’ll keep the gym open an extra hour just for him while I do paperwork.”

Mike: “That’s nice, but Jarred really needs to learn social skills and team work. If I come with him, can he continue to come to the gym?”

Lois: “Okay...if you can teach him social skills, I suppose that’s okay.”

Later, Mike and Jarred are playing basketball in the driveway of Jarred’s house.

Mike: “Hey, I talked to the lady at the gym and she said you can still come to the gym, but I gotta teach you a little about basketball first. What was that name those guys were calling you?”

Jarred: “Fouler-baby.”

Mike: “Let me show you something. Why don’t you try to defend me?”

Mike dribbles the ball as Jarred nudges really close, blocking Mike’s every move.

Mike: “Whoa! You can’t get that close to people, or else it’s a foul. Let me show you how to do it.” (Mike shows the proper way to block a shot.) “See how I’m not touching you? Why don’t you try it.”

Jarred blocks Mike’s shot successfully—just the way Mike showed him.

Mike: “Good defense! Good job, Jarred!”

Weeks later, Mike and Jarred are inside Lois’ office at the health club.

Mike: “We’ve been coming to the gym for about two weeks now and Jarred’s having a really good time. We wanted to see how he’s doing.”

Lois: “Okay, I guess. Lucky for you so far.”

Mike: “Like I said, Jarred has really enjoyed himself and we were hoping he could join your league team.”

1. What roles do Mike play?
2. How is Mike an Advocate?
3. Does Jarred’s quality of life change as a result of Mike playing the different roles?

ACTIVITY

Individual Provider Roles and Responsibilities

Directions: Read the following scenario. Draw a line from each activity to its matching role. Some roles will have more than one activity attached to them.

Mary, a new IP, asked Tom, a fellow IP, to tell her what he does during a typical work day. Here are some of the activities Tom did:

ROLES

Partner	<ul style="list-style-type: none"> ▪ Tom talked to Martha, the case manager, about getting ready for A.J.'s planning meeting scheduled for Tuesday. Tom would like to see A.J. get a bus pass for the Tacoma area now that he uses the bus to go to work. ▪ Tom assisted A.J. with his medication.
Teacher	<ul style="list-style-type: none"> ▪ Tom spent time teaching A.J. how to put a tape into his own VCR.
Ambassador	<ul style="list-style-type: none"> ▪ Tom helped A.J. and Marissa make breakfast. ▪ Tom talked with Marissa about her parents. Marissa feels that her parents are too controlling. ▪ Tom helped A.J. clean up his room.
Advocate	<ul style="list-style-type: none"> ▪ Tom talked to Martha about tacking down a piece of carpet that A.J. tripped over. ▪ Tom helped A.J. pick out matching clothes to wear.
Supporter	<ul style="list-style-type: none"> ▪ Tom talked to A.J.'s boss at Starbucks. He answered his questions about A.J.'s disability. ▪ A.J.'s counselor was late for an appointment, and Tom could tell that A.J. was upset. Tom went for a short walk with A.J. to help him settle down. ▪ Tom helped Marissa make a list of questions for the doctor before he took her to her appointment.

Teaming with Others to Support Individuals

Another important role that the IP plays is that of a Team Member. As an IP, you are a member of several teams: the team of staff who work to support individuals in the home, each person's individual support team, and each individual's care team. People who might be part of these teams include: individuals and their families; the case manager and other IPs, both in the home and at a day

or work site; health care professionals, and other representatives from community agencies.

You will find that working as part of a team is often better than working alone. Sharing information and ideas with team members leads to creative planning and problem solving. ***In order to protect your employer's privacy, only share information with people named on the Individual Service Plan.***

The Individual Provider Profession

People like you, who support individuals in their daily lives, were not always considered "professionals." More recently, the importance of the challenging work that you and other IPs perform has gained broad recognition and acknowledgement as a profession.

Specific knowledge, skills, and commonly agreed-upon standards for professional conduct are what separate a "job" from a "profession." This training focuses on the skills, knowledge, and abilities that have been identified by individuals receiving Medicaid services, individual providers, and others as critical to satisfactory job performance.

Nationwide, IPs have joined together to form a professional organization called the National Alliance for Direct Support Professionals (NADSP). The NADSP has developed a set of **professional ethics** (standards for professional conduct) for IPs. The complete text of the NADSP Code of Ethics is in Appendix A.

Information about how to get connected with this organization is included in the Resources section of this manual. NADSP has a Web site and newsletter written by and for IPs that contains very helpful and supportive information for IPs.

Values to Guide Your Work

A **guiding principle** of long-term in-home care in Washington state is that services enable people to remain in their own home and community, whenever possible.

The overall **mission** of Washington state's long-term in-home care system:

- helps individuals and their families develop and maintain self-sufficiency;
- remain valued and contributing members of their community; and
- maximizes quality of life by managing services that are high quality, cost effective, and responsive to individual needs and preferences.

The long-term in-home care system in Washington is also guided by the following **values**:

- Individual worth, dignity, respect, self-direction and self-sufficiency.
- Freedom from abuse, neglect, abandonment, financial exploitation, and discrimination.

Washington's long-term in-home care system also **promotes** quality, safety, access, accountability, and non-discrimination in its service system.

SOURCE: Adapted from Department of Social and Health Services Aging and Adult Services *Strategic Plan 2006-2011*.

Individual providers have very important job responsibilities that significantly affect their employer's life. Maintaining dignity and respect while also supporting an individual to maintain self-sufficiency requires special skills. You can do this by:

- Making sure that how your employer wants things done is incorporated into how you perform his/her personal care.
- Doing everything possible to ensure your employer's dignity and privacy are respected.
- Working with your employer to encourage them to do as much as possible on their own.
- Knowing, taking pride in, and performing your role as a member of the care team. This includes:
 - Monitoring changes in your employers health (physical and mental) condition
 - Knowing when and what to report to the appropriate care team member(s)
- Identifying problem situations and taking the necessary action to support your employer's well-being.
- Responding to emergencies without supervision if necessary.

SOURCE: Adapted from Department of Social and Health Services, Home and Community Services, *Revised Fundamentals of Caregiving Learner's Guide, 2003*.

The Individual Provider Toolbox

Whether you are working independently or with a team, you will need a set of “tools”—basic skills and knowledge—to help you successfully meet the daily challenges of your job. Just as a carpenter cannot do a job without a hammer and nails, an IP cannot provide the best possible support to individuals without the IP tools. Tools in the IP Toolbox are:



Ethics: enable the IP to make ethical decisions



Observation: enables the IP to observe people and places for things that could affect an individual’s health and well-being



Communication: enables the IP to communicate in a variety of ways



Decision making: enables the IP to choose the best course of action with the information at hand



Documentation: enables the IP to document important information about individuals and events

Many situations in your work call for using several tools at the same time.

For example, if an individual is sick, you might use every tool in the Individual Provider Toolbox:

- **Ethics** to guide you in promoting the individual’s physical well-being by helping to identify the illness and ensuring timely medical treatment with dignity and respect.
- **Observation** by using your senses to identify changes that are likely to be signs and symptoms of illness. You might *see* the individual rubbing her stomach, *feel* her skin is cold and clammy, or *hear* her moaning and saying “my stomach hurts.”
- **Communication** to ask questions about someone’s pain such as, “How long has it hurt you?” Communication also means listening and understanding an individual’s response.
- **Decision making** to decide how to respond to the individual’s illness based on what you have observed and what has been communicated. For example, “Do I need to call the case manager, family or doctor, or take her directly to the emergency room?”
- **Documentation** to record information about the illness to bring to the doctor’s appointment.

Scenario: The Individual Provider (IP) Toolbox

Featuring



Howard

A 72 year-old man



Steve

Howard's individual
provider



Dr. Smith

Howard's doctor

Howard is sitting on the examining table in Dr. Smith's office. Steve, Howard's IP, is sitting off to the side as Dr. Smith talks with Howard, who has not been feeling well.

Doctor: "So, Howard, you've been sick for ten days and you're not getting better and now you have a headache. You probably have an acute sinus infection in addition to your bronchitis. This will prolong your illness. I think good medication will make you feel better. Are you currently taking any medications?"

Howard, unsure, looks to Steve for an answer.

Steve: "He takes medication for his heart."

Doctor: "That shouldn't be a problem. Are you allergic to penicillin or other medication?"

Howard looks again to Steve for an answer.

Steve: "Right now he doesn't have any allergies that we know of."

Doctor: "I'm going to prescribe you Amoxicillin, which will help fight your sinus infection. I want you to take one pill a day for ten days. Keep taking it even if you feel better. The other thing I'm going to prescribe is a cough medicine. Take one teaspoon every six hours as needed for your cough. Any questions?"

Steve: "Are there any side effects or anything? Anything else you can think of, Howard?"

(continued)

Doctor: “Well, an allergic reaction is a side effect of Amoxicillin, but since he hasn’t had an allergic reaction before, he probably won’t have one this time. But, if he gets short of breath, develops a rash or hives, stop taking the medicine and call us immediately. When you pick up your medication at the pharmacy, the pharmacist will give you a medication sheet with detailed information. If you have any questions about the medicine, go ahead and ask the pharmacist.”

Steve: “Sounds good. That’s all I can think of. Howard, is there anything you want to tell the doctor while we’re here?”

Howard: “No.”

1. How did the IP use Ethics?
2. How did the IP use Communication?
3. How did Howard feel?

The Individual Provider Toolbox: Additional Information

ETHICS



Ethics are rules about how people think they and others should behave. People's ethics are influenced by a variety of factors, including culture, education and the law.

- The NADSP developed a Code of Ethics (Appendix A) to guide the behavior of IPs. Refer to the Code when in doubt about the most ethical thing to do.

- Here is a condensed version of the NADSP Code of Ethics:

1. Advocacy: As an IP, I will work with the individuals I support to fight for fairness and full participation in their communities.

2. Person-Centered Supports: As an IP, my first loyalty is to the individual I support. Everything I do in my job will reflect this loyalty.

3. Promoting Physical and Emotional Well-Being: As an IP, I am responsible for supporting the emotional, physical, and personal well-being of individuals receiving support while being attentive and energetic in reducing their risk of harm.

4. Integrity and Responsibility: As an IP, I will support the mission of my profession to assist individuals to live the kind of life they choose. I will be a partner to the individuals I support.

5. Confidentiality: As an IP, I will protect and respect the confidentiality and privacy of the individuals I support.

6. Fairness: As an IP, I will promote and practice fairness for the individuals I support. I will promote the rights and responsibilities of the individuals I support.

7. Respect: As an IP, I will respect the individuals I support and help others recognize their value.

8. Relationships: As an IP, I will assist the individuals I support to develop and maintain relationships.

9. Self-Determination: As an IP, I will assist the individuals I support to direct the course of their own lives.

OBSERVATION



Observation is noticing change in an individual's health, attitude, appearance, or behavior.

- Get to know the individual so you can tell when something changes.
- Use your senses of sight, hearing, touch, and smell to observe signs or changes.
- Get to know the individual's environment and look for things that may impact an individual's and other's safety and well being.

COMMUNICATION



Communication is understanding and being understood.

- Listen carefully to what is being communicated through words and behavior.
- Repeat back what was communicated to confirm understanding.
- Ask questions to gain a more complete understanding.
- Be respectful.

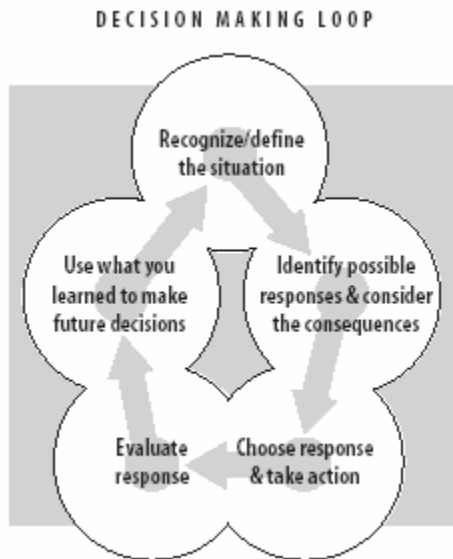
The Individual Provider Toolbox: Additional Information

DECISION MAKING



Decision making is choosing the best response to a situation with the information that is available to you. Decision making is an ongoing process.

- Recognize/define the situation
- Identify possible responses and consider the consequences.
- Choose a response and take action.
- Evaluate how your response worked.
- Were the consequences positive? If not, what could have made it work better?
- Use what you learned to make decisions in the future.



DOCUMENTATION



Documentation is a written record.

- The IP should keep consumer/employer notes for the following important, non-routine events in an individual's life: medical and dental visits, illness/injury, special incidents, community outings, overnight visits away from the home, and communications with the individual's physician. (Note any changes in behavior or appearance).
- Do not document personal opinions, just the facts (for example, who, what, when, and where).
- Be specific when describing behaviors.
- Record what the person actually said or describe non-verbal attempts to communicate.
- Describe the event from beginning to end.
- Be brief.

Individuals with Functional and Developmental Disabilities

Who are the people you support? First, they are **individuals**. The people you support are children and adults, male and female, and come from interesting backgrounds just like you. They have many unique preferences and qualities that you will get to know as you get to know them. What the individuals you support have in common is that they have functional or developmental disabilities.

Functional disabilities are caused by a number of things: illness, stroke, brain injury, or as a result of congenital disability. Symptoms of functional disability include pain, weakness, stiffness or paralysis. Persons with functional disability require assistance with one or more daily activities because they have varying levels of self-sufficiency or mobility.

Additionally, you may also support children who have high physical or personal care needs. Other potential employers are older individuals who receive in-home services that allow them to remain in their own communities. Working with these individuals may present challenges, but the rewards far outweigh those challenges.

An IP working with aging adults may want to consider specialized training or self-study to adequately support persons with cognitive or behavioral issues:

- Dementia
- Delirium
- Depression
- Anxiety/grief
- Mental illness
- Personality disorders

You may also work for a person who has an age-related illness, such as Parkinson's or Alzheimer's disease.

Following is some basic information about the causes and kinds of developmental disabilities. You are not expected to know everything about every type of developmental disability. However, it is important that you know and understand the types of disabilities that the individuals you work with have in order to provide them with the best possible service and support.

Your employer may be:

- Functionally disabled
- Developmentally disabled
- Aged
- A child

**Remember that above all,
your employer is an
INDIVIDUAL.**

What is a Developmental Disability?

A **developmental disability**, as defined by Washington state law:

- Begins before someone reaches 18 years of age
- Is something that goes on throughout an individual's life
- Is a substantial disability for the individual
- Often means there is a need for some kind of assistance in the individual's daily life.

Developmental disabilities include mental retardation, cerebral palsy, epilepsy, and autism. Also included in the legal definition are people who need the same kinds of support as those who have mental retardation. It does not include people who have only physical, learning, or mental health challenges.

Causes of Developmental Disability

Many things can cause a developmental disability, such as:

- The mother having a serious illness, poor eating habits, or poor health care, or the fact that she smokes, drinks alcohol, or uses drugs.
- A serious accident, abuse, lead poisoning, or poor nutrition.
- Chemical or chromosomal differences (like Down's Syndrome) or an inherited condition.
- A lack of oxygen to the brain, low weight, or a difficult birth.

While keeping the above causes in mind, remember that often, the cause is not known and can happen to any family.

What is a Functional Disability?

A functional disability may include one or all of the following:

- limitations in or inability to perform a variety of physical activities
- serious sensory impairment
- long-term care needs
- use of assistive devices

Functional disabilities include cognitive, communication, coordination or manipulation, hearing, mobility, vision, learning or mental health challenges. It does not include people who have developmental disabilities.

Causes of Functional Disability

Functional disabilities can happen to anyone, at any time. Illness, stroke, brain or spinal cord injury or a condition a person is born with may be causes of functional disability. Arthritis, diabetes, coronary artery disease, cancer or cognitive impairment also may lead to functional disability.

The Disabled

By Kathleen Snow

According to stereotypical myths, they are:
People who *suffer* from the *tragedy* of birth defects.
Paralegic heroes who *struggle* to become *normal* again.
Victims who *fight* to *overcome* their *challenges*.
Categorically they are called *retarded*, *autistic*, *blind*,
deaf, *learning disabled*, etc., etc., etc.—*ad naseum!*
Who are they, really?
Moms and Dads...Sons and Daughters...
Employees and Employers...Friends and Neighbors...
Students and Teachers...Leaders and Followers...
Scientists (Stephen Hawking)...
Movie Stars...(Marlee Matlin)...
They are people.
They are people first.

Major Kinds of Developmental Disabilities

The following graph illustrates the major kinds of developmental disabilities: mental retardation, cerebral palsy, autism and epilepsy. The graph also tells you what those disabilities might look like and how that might impact how you support individuals.

<i>Developmental Disability</i>	<i>Characteristics</i>	<i>Notes for IP</i>
Mental Retardation	<ul style="list-style-type: none"> ▪ Learns slowly. ▪ Has a hard time remembering things that are learned. ▪ Has a hard time using what is learned in a new situation. ▪ Thinks about things in more real-life or concrete ways. ▪ Keeps learning and developing throughout life as we all do. 	<ul style="list-style-type: none"> ▪ There are different levels of mental retardation from mild to severe. This means that individuals need different types of assistance in daily living. ▪ Very different from mental illness. Some people who have mental retardation also have mental illness, but most people who have mental illness do not have mental retardation.
Cerebral Palsy	<ul style="list-style-type: none"> ▪ Awkward or involuntary movements. ▪ Poor balance. ▪ An unusual walk. ▪ Poor motor coordination. ▪ Speech difficulties. 	<ul style="list-style-type: none"> ▪ “Cerebral” refers to the brain and “palsy” to a condition that affects physical movement. ▪ Ranges from mild to severe. ▪ Not a contagious disease—you can’t “catch” it. ▪ People can lead more independent lives through physical therapy and the use of special devices (for example, computers and wheelchairs). ▪ May also have mental retardation and/or epilepsy.
Autism	<ul style="list-style-type: none"> ▪ Generally has a difficult time making friends. ▪ May have unusual emotional responses, such as laughing at a car accident. ▪ Generally has a difficult time communicating with other people. ▪ May repeat words and/or body movements. 	<ul style="list-style-type: none"> ▪ Affects people in many different ways. The causes are not very well understood. ▪ Some people who have autism also have mental retardation.
Epilepsy	<ul style="list-style-type: none"> ▪ Has seizures. ▪ May become unconscious. ▪ Movement or actions may change for a short time. 	<ul style="list-style-type: none"> ▪ Epilepsy is sometimes called a seizure disorder. ▪ Individuals with epilepsy may also have mental retardation, cerebral palsy, or autism.
Other		<ul style="list-style-type: none"> ▪ Includes people who meet the same kinds of support as those who have mental retardation. ▪ It does not include people who have only physical, learning or mental health challenges. ▪ Examples are conditions like Neurofibromatosis, Tuberous Sclerosis, and Prader-Willi Syndrome.

Functional Disabilities by Type

The following chart illustrates the major kinds of functional disabilities: cognition, communication, coordination or manipulation, hearing, mobility and vision.

<i>Functional Disability</i>	<i>Characteristics</i>
Cognition	Cognitive disability involves the brain's ability to process, retrieve, store and manipulate information. It is usually manifested in impairments to attention, orientation and memory. Cognitive disability includes deficits in such tasks as problem-solving, judgment, information processing (reading, writing, mathematics) and behavior.
Communication	Communication disability involves the process of interpreting the words or movements of others and expressing one's own thoughts and emotions through words, writing and body language. This disability often manifests in problems of oral speech, listening skills and in written communication.
Coordination or Manipulation	Disability in coordination affects fine manipulation by the hands such as fingering, feeling, grasping, pinching and handling. Tasks that can be impaired include typing, writing, eating, bathing, grooming, dressing oneself, telephoning, handling money, and in general any tasks including use of the hands for manipulation.
Hearing	Hearing disability includes any impairment of hearing that limits the ability to detect and discriminate among sounds that vary over ranges of pitch and loudness, frequently manifesting in poor auditory communication. Hearing disability can also include difficulty maintaining attention to sounds or localizing sounds (identifying the direction and distance of sound sources).
Mobility	Mobility disability includes impairments in movement that involves change of position or location. Bed mobility refers to changing position side-to-side, wheelchair mobility refers to propelling the wheelchair on various surfaces as well as managing wheelchair parts, and functional ambulation refers to walking with some aid, such as crutches, to move about. Limitations in mobility may affect standing, walking, lifting, carrying, balancing, stooping, kneeling and stamina/endurance to accomplish these tasks.
Vision	Disability in vision manifests as impairments to near or far vision, color discrimination, night vision, peripheral vision, glare sensitivity and depth perception. Visual disability varies widely in kind and degree, and in the more advanced cases includes blindness. Visual disability can affect a very broad range of activities and tasks.

Developmental Delays

A developmental delay is a very large difference between a young child's abilities and what is usually expected of children the same age. ("Young" is defined as up to 36 months of age.) Infants and toddlers who have a developmental delay can receive early intervention services. These services support the child in learning the things that will help him or her start to catch up.

Special Issues for an Aging Population

People are living longer—the latest census indicates the 85 years and older age group is the fastest growing population group nationally. Not all seniors will require in-home care, but many seniors will experience a decline in functioning and will need in-home assistance at some point. In Washington, just over half of all seniors served by the Department of Social and Health Services are assisted in their own homes, rather than more costly nursing homes or other residential settings.

When working with an older individual, it is important to know that as a person ages, their bodies go through changes—our bodies shift from growing to maintaining. This means that the body systems slow down and we don't make new cells as fast as we used to. Each person ages differently, and the aging process is affected more by a person's physical condition than his or her actual age. Although there are some conditions more common in an older adult, very few diseases or functional changes are a normal part of aging. It is a myth that growing old has certain problems.

There are psychological and social changes as we age. Some changes are positive and some are not. Positive changes include:

- Enjoying family members
- Enjoying hobbies
- Being the “wise” elder
- Having more leisure time

Individuals with Disabilities Are People First

While it's important to learn about the names and causes of developmental disabilities, **individuals with developmental or functional disabilities are people first**. One group of self-advocates came up with the saying, “Label Jars, Not People.” For example, the subtle difference between calling Joe “a person with autism” rather than “an autistic person” is one that acknowledges Joe as a person first. This is one example of what is called **People First Language**. A good way to ensure that you are using People First Language is to begin describing people with the words “individual,” “person,” “man,” or “woman.”

“The difference between the right word and the almost right word is the difference between lightning and the lightning bug.”

- Mark Twain

The Golden Rule vs. the Platinum Rule

It is not enough to use People First Language to show respect for individuals. It is also important to demonstrate **People First Behavior**. What does that mean? It means that:

- You take the time to learn about an individual's needs, strengths, and preferences.
- You do not assume that you know what is best.
- Your manner of supporting individuals reflects their needs, strengths, and preferences.

The old rule was the **Golden Rule**: Treat others the way you would want to be treated. The new rule is the **Platinum Rule**: Treat others as they want to be treated.

Person First Language: Guidelines For Discussing People With Disabilities

It's the "Person First" - THEN the Disability

If you saw a person in a wheelchair unable to get up the stairs into a building, would you say "there is a handicapped person unable to find a ramp?" Or would you say "there is a person with a disability who is handicapped by an inaccessible building?" What is the proper way to speak to or about someone who has a disability?

Consider how you would introduce someone - Jane Doe - who doesn't have a disability. You would give her name, where she lives, what she does or what she is interested in - she likes swimming, or eating Mexican food, or watching Robert Redford movies.

Why say it differently for a person with disabilities? Every person is made up of many characteristics - mental as well as physical - few want to be identified only by their ability to play tennis or by their love for fried onions or by the mole that's on their face. Those are just parts of us.

Person first language

In speaking or writing, remember that children or adults with disabilities are like everyone else - except they happen to have a disability. Therefore, here are a few tips for improving your language related to disabilities:

1. Speak of the person first, then the disability.
2. Emphasize abilities, not limitations.
3. Do not label people as part of a disability group - don't say "disabled", say "people with disabilities."
4. Don't give excessive praise or attention to a person with a disability; don't patronize them.
5. Choice and independence are important; let the person do or speak for him or herself as much as possible; if addressing an adult, say "Bill" instead of "Billy."
6. A disability is a functional limitation that interferes with a person's ability to walk, hear, talk, learn, etc. use handicap to describe a situation or barrier imposed by society, the environment, or oneself.

Person-First Language:

The practice of referring to persons with disabilities with the term denoting disability following terms referring to them as an individual. Person-first avoids impersonal, negative and medical terminology.

SAY...	INSTEAD OF...
child with a disability	disabled or handicapped child
person with cerebral palsy	palsied, or C.P., or spastic
person who has...	afflicted, suffers from, victim
without speech, nonverbal	mute, or dumb
developmental delay	slow
emotional disorder or mental illness	crazy or insane
deaf or hearing impaired	deaf and dumb
uses a wheelchair	confined to a wheelchair
person with mental retardation	retarded
has a learning disability	is learning disabled
non-disabled	normal, healthy
has a physical disability	crippled
congenital disability	birth defect

SOURCE: Adapted from "Tools for Teachers" by the New Jersey Council on Developmental Disabilities.
<http://www.autism-mi.org/aboutautism/TeacherTools12-04.html>

OPTIONAL ACTIVITY

Stereotypes of Individuals with Disabilities

Directions: Write down the stereotypes of people with functional or developmental disabilities that you have heard and then consider the following questions.

How many stereotypes are negative?

Why are so many negative?

What impact does it have on the people whom you will work with if you believe these stereotypes?

Does anyone know of a person without a disability who fits one or more of these stereotypes?

Do you think these stereotypes ever affect the work that IP's do? If so, how?

How can IP's overcome these stereotypes?

PRACTICE AND SHARE

Think of a time when you helped to add to the quality of an individual's life. What exactly did you do to add to the quality of an individual's life? How do you know it added to the quality of an individual's life?

SESSION ONE – THE INDIVIDUAL PROVIDER: QUIZ

1. What is the main reason IP’s are required to take the *Becoming a Professional Individual Provider* training?

- A) To help the IP improve the quality of life of individuals receiving in-home services.
- B) To give the IP firm control over the lives of individuals with developmental disabilities.
- C) To enable IP’s to earn more money for the work they do.
- D) To reduce the responsibility IP’s have for caring for individuals with developmental disabilities.

2. Which of the following is a role the IP is expected to play?

- A) Advocate
- B) Parent
- C) Boss
- D) Disciplinarian

3. Which of the following is an example of “People First” Language?

- A) Victim
- B) Handicapped
- C) Individual with a developmental disability
- D) Mentally retarded person

4. Which of the following is true about developmental disabilities?

- A) Developmental disabilities always begins before someone is born.
- B) Individuals usually outgrow developmental disabilities by the time they retire.
- C) Individuals with developmental disabilities are capable of learning and growing.
- D) Most individuals with severe to profound developmental disabilities need very little assistance in their daily lives.

5. Wanda has difficulty walking and speaking clearly. Sometimes she jerks her head to the side and moves her arms around even though she does not intend to make these movements. Based upon this description, which one of the following disabilities is Wanda most likely to have?

- A) Mental retardation
- B) Cerebral Palsy
- C) Autism
- D) Epilepsy

Read this story and then answer questions 7 through 10.

Mary noticed that Marissa was rubbing her knee. She asked Marissa why she was doing that. Marissa answered that she had tripped on a crack in the sidewalk, fallen, and hurt her knee. Marissa asked her to show her what her knee looked like. There was a very large bruise and swelling. Mary called the doctor to make an appointment for that day and tried to make Marissa comfortable until the appointment. Later, Mary wrote about what happened in her log so that she could inform the family and case manager.

7. When Mary noticed that Marissa was rubbing her knee, she was using _____ from the IP Toolbox.

- A) Documentation
- B) Ethics
- C) Decision making
- D) Observation

8. When Mary asked Marissa why she was rubbing her knee, she was using _____ from the IP Toolbox.

- A) Ethics
- B) Communication
- C) Observation
- D) Decision making

9. When Mary looked at Marissa's knee and called the doctor, she was using _____ from the IP Toolbox.

- A) Observation
- B) Communication
- C) Documentation
- D) Decision making

10. When Mary made a doctor's appointment for the same day and tried to make Marissa comfortable before the appointment, she was using _____ from the IP Toolbox.

- A) Communication
- B) Observation
- C) Ethics
- D) Documentation