Trainer Resource Guide

1. The Direct Support Professional

Trainer Guide: SESSION 1

Materials

- LCD projector and computer
- Flash Drive
- Chart paper
- Colored markers
- Masking tape

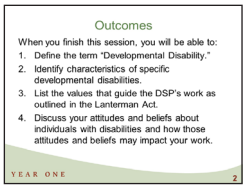
Welcome

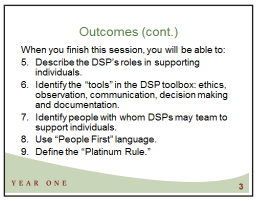
Show Slide #1: The Direct Support Professional (DSP)

- In this session, you will learn about your role as a Direct Support Professional assisting individuals with disabilities to have a better quality of life.

Show Slides #2 and #3: Outcomes

- Review outcomes for the session.





Student Resource Guide: SESSION 1

The Direct Support Professional

OUTCOMES

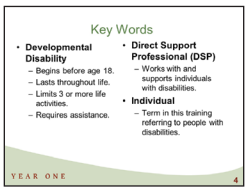
When you finish this session, you will be able to:

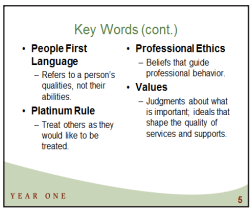
- Define the term “developmental disability.”
- Identify characteristics of specific developmental disabilities.
- List the values that guide the Direct Support Professional (DSP) work as outlined in the Lanterman Act.
- Discuss your attitudes and beliefs about individuals with disabilities and how those attitudes and beliefs may impact your work.
- Describe the DSP’s roles in supporting individuals.
- Identify the “tools” in the DSP toolbox: ethics, observation, communication, decision making, and documentation.
- Identify people with whom DSPs may team to support individuals.
- Use “People First” language.
- Define the “Platinum Rule.”

Key Words

Show Slides #4 and #5: Keywords

- Review key words for the session.





KEY WORDS

Key Word	Meaning	In My Own Words
Developmental Disability	A developmental disability begins before someone reaches 18 years of age; lasts throughout an individual's life; greatly limits three or more major life activities; and often means there is a need for some kind of assistance.	
Direct Support Professional (DSP)	You are a DSP. A DSP works with and supports individuals with developmental disabilities where they live and work.	
Individual	How this training refers to individuals with intellectual/ developmental disabilities. 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 beliefs to guide one's professional behavior.	
Values	Judgments about what is important in life. Ideals that shape the quality of services and supports.	

ACTIVITY: What Do You Want to Know?

- Read directions aloud.
- Ask for student volunteers to share answers.
- Make note of student answers and link back to student knowledge and interests as appropriate as you review session content.
- At the end of this session you will return to this activity to give students an opportunity to answer the third question.

A C T I V I T Y

What Do You Want to Know?

Directions: *Think about the topic of this training session. Answer the first two questions in the space provided below. You will come back to this page at the end of the session to answer the last question.*

What do you **already know** about the DSP's roles and responsibilities in supporting individuals with developmental disabilities to have a better quality of life?

What do you **want to know** about the DSP's roles and responsibilities in supporting individuals with developmental disabilities to have a better quality of life?

To be answered at the end of the session, during review:
What **have you learned** about the DSP's roles and responsibilities in supporting individuals with developmental disabilities to have a better quality of life?

Trainer Guide: SESSION 1

Introduction

Show Slide #6: Video: Focus Group, Quality of Life Conversation

- Click on the icon to show the video.
- Show focus group only (approximately 10 minutes).

Show Slide #7: Activity: <u>What Adds to the Quality of Your Life?</u>

- Read the directions aloud.
- Activity can be done as a class. Write students responses on a flip chart.

  Or
- Activity can also be done in smaller groups. Have one representative from each group share some of the solutions that their group discussed.
- Note to Trainer: The purpose of this activity is to show that everyone has interests and preferences, regardless of their developmental abilities. It is the job of the DSP to assist individuals they support in achieving their wants, needs and desires. Students will learn methods and strategies to assist the individuals they support to lead the quality of life they choose.

Introduction

What is the purpose for the Direct Support Professional training?

The purpose of the DSP training is to build your skills to promote the health, safety, and well-being of individuals with intellectual/developmental disabilities, which will lead to a better quality of life.

Promoting a better quality of life for the individuals with disabilities who you support will likely lead to a more rewarding professional life for you! There is nothing better than a situation in which everyone wins!

DSP Training for a Better Quality of Life

So what does "quality of life" mean? It can mean 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 satisfied with their lives.

A C T I V I T Y

What Adds to the Quality of Your Life?

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

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

Better Quality of Life

- Read what people with intellectual/developmental disabilities said about what “quality of life” means to them.
- Ask students to raise their hands for each one of the things that are necessary for them to have a good quality of life, too.

DSP Training for a Better Quality of Life

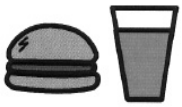
Now, let's see what some individuals with intellectual/developmental disabilities have to say about what quality of life means to them. A number of individuals living throughout the state of California were asked, "What does quality of life mean to you? What things are important in your life (things 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

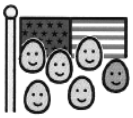
I cook whenever I want

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

Better Quality of Life (cont.)

Show Slide #8: Individuals Want Choices

- Review content in the Student Guide.

DSP Training for a Better Quality of Life (cont.)

In many of the areas listed on page S-5, the individuals surveyed felt they were doing pretty well; however, individuals said they specifically wanted to make more of their own choices in the area of relationships, personal care, and personal freedom.

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.

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

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.

Individuals had some very specific things to say to the people who support them: that means you. They want:

- To have more say about the medications they take,
- To wear clean clothes,
- To decide on their own bedtime,
- 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.*

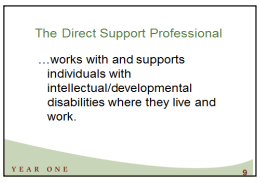
As we go through this training, listen, learn, and think about what individuals with intellectual/developmental disabilities have to say about what is important to them and how you can apply what you learn in supporting the individuals to have a better quality of life.

*Excerpted and Adapted from Department of Developmental Service's Consumer Advisory Committee,

Community Conversations with People with Developmental Disabilities in California.

The Direct Support Professional

Show Slide #9: The Direct Support Professional



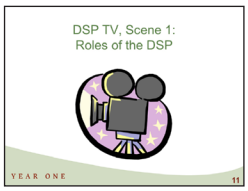
- This information relates to a learning outcome and may be covered on the quiz.

  Outcome: Describe the DSP's roles in supporting individuals.
- Read the definition of DSP aloud.

Show Slide #10: DSP Roles

- Read the descriptions of each role aloud from the Student Guide.
- All of the roles the DSPs play have a common focus about the worth of the individual and supporting them to live the kind of life they hope and dream about.
- DSPs do not play the role of a boss or parent.
- Remind the DSPs that their role is to support the decisions of individuals and/or the individual's family, and to always ensure the health and safety of every individual in their care.

Show Slide #11: DSP TV video, Scene 1: Roles of the DSP



- Click on the icon to show the video.
- Read and discuss questions at end of Scene 1.

Answers:

- What roles does Mike play?

  Mike is a Partner, Teacher, Ambassador, Advocate and Supporter.
- How is Mike an Advocate?

  Mike is an Advocate when he calls the health club on Jason's behalf. Mike is also an Advocate when he talks to the health club director about Jason playing in their basketball league.
- Does Jason's quality of life change (as a result of Mike playing the different roles)?

  Yes. Jason's quality of life is probably better because he has the opportunity to participate in an activity he enjoys.

The Direct Support Professional

A **Direct Support Professional (DSP)** works with and supports individuals with intellectual/developmental disabilities in the places they live and work. DSPs perform their jobs in licensed homes, day programs, supported or independent living environments, and work sites. A DSP has many important roles to play. You are:

- A PARTNER - assisting individuals to lead independent lives and participate in and contribute 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 interact with individuals with intellectual/developmental disabilities as neighbors, friends, and co-workers.
- An ADVOCATE - supporting individuals to exercise their rights and responsibilities.
- A SUPPORTER - seeking to understand the likes, dislikes, hopes, and dreams of individuals they support and working with them 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 lives they choose. The DSP is a Partner, Teacher, Ambassador, Advocate, and Supporter. The DSP is not a Boss or one who orders people around and makes them do things they may not want to do. Likewise, the DSP is not a Parent to the individuals they support. The job of the DSP carries a great deal of responsibility, and it is easy to get these roles confused. Unlike a parent, legal guardian, or conservator, the DSP does not have the authority to make important life decisions for individuals they work for and with. Instead, the individuals themselves, with the help of parents, legal guardians, conservators and service coordinators as appropriate, make decisions about their own lives.

Optional Activity: DSP Roles and Responsibilities

- Note to trainer: There is no PowerPoint slide for this optional activity.
- Read the directions aloud.
- Assist students to match the roles with the activity.
- Use the first role Partner, and help students find a correct answer for this role.
- DSPs may also play many different roles in the course of one activity.
- Remind students that as a DSP their primary role is to support individuals to be safe, happy, and healthy.
- Students can refer to page S-7 if necessary

Answers:

Partner

- **Tom helped A.J. with his medication.**
- **Tom helped A.J. and Marissa make breakfast.**
- **Tom helped A.J. clean up his room.**
- **Tom helped A.J. pick out matching clothes to wear.**
- **Tom helped Marissa make a list of questions for the doctor before he took her to the appointment.**

Teacher

- **Tom spent time teaching A.J. how to put a DVD into his own DVD player.**

Ambassador

- **Tom talked to A.J.'s boss from Starbucks. He answered his questions about A.J.'s disability.**

Advocate

- **Tom talked to Martha, the home administrator about getting ready for A.J.'s IPP meeting scheduled for Tuesday. A.J. would like to get a bus pass for the Roseland area now that he uses the bus to go to work.**
- **Tom talked to Martha about tacking down a piece of carpet that A.J. tripped over.**

Supporter

- **Tom talked to Marissa about her parents. Marissa feels that her parents are too controlling.**
- **A.J.'s Service Coordinator 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.**

OPTIONAL ACTIVITY

DSP 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 (refer to page S-7 if necessary).*

Mary, a new DSP, asks her co-worker, Tom, to tell her about what he does during a typical work day. She wants to know more about what she's expected to do as a DSP. Tom counts on his fingers some of the activities he did over the past week. As he lists the activities, he realizes that he doesn't have enough fingers to count them all! Here are some of the activities Tom did:

ROLES

Partner

Teacher

Ambassador

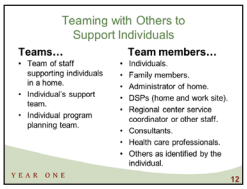
Advocate

Supporter

- Tom talked to Martha, the Home Administrator, about getting ready for A.J.'s IPP meeting scheduled for Tuesday. A.J. would like to get a bus pass for the Roseland area now that he uses the bus to go to work.
- Tom helped A.J. with his medication.
- Tom spent time teaching A.J. how to put a DVD into his own DVD player.
- 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.
- 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.
- Tom talked to A.J.'s boss at Starbucks and answered his questions about A.J.'s disability.
- A.J.'s Service Coordinator 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 calm down.
- Tom helped Marissa make a list of questions for the doctor before he took her to her appointment.

Trainer Guide: SESSION 1

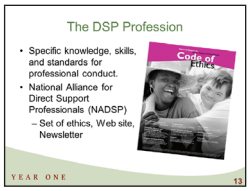
Show Slide #12: Teaming with Others to Support Individuals



- This information relates to a learning outcome and may be covered on the quiz.

  Outcome: Identify people with whom DSPs may team to support individuals.
- Review the information in the Student Guide.
- Tell students that they will be learning about a very important team, the Individual Program Planning team, also called the IPP team, in the next session.
- Remind students that a key element of a successful team is trust.
- Ask students what "trust" means to them.
- Possible answers: confidentiality, respect, showing one cares, helping with personal hygiene with dignity, respecting privacy, honesty, reliability, etc.

Show Slide #13: The DSP Profession



- DSPs were not always considered professionals, but that is changing.
- This training focuses on the skills, knowledge, and abilities that administrators, DSPs and other experts say are critical to satisfactory job performance.
- There is a national professional organization for DSPs called the National Alliance of Direct Support Professionals (NADSP).
- NADSP has developed a set of professional ethics called the Code of Ethics for the profession. The Code can be found in Appendix 1-A at the end of this chapter.
- NADSP has a website and newsletter written by and for DSPs that contains very helpful and supportive information. The NADSP website is www.nadsp.org.

Teaming with Others To Support Individuals

The DSP is 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 planning team.

People who might be on these teams include: individuals and their families; the administrator of the home and other DSPs, both in the home and at a day or work site; regional center staff, consultants, 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.

The DSP 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 DSPs perform has gained broad recognition and appreciation 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 administrators, direct support professionals, and others as critical to satisfactory job performance.

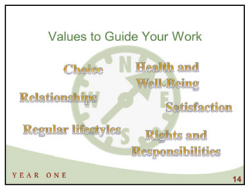
Nationwide, DSPs have joined together to form a professional organization called the National Alliance for Direct Support Professionals (NADSP). The NADSP has developed a set of professional ethics (standards for professional conduct) for DSPs.

The complete text of the NADSP Code of Ethics is in Appendix 1-A. Information about how to get connected with this organization is included in the resources section of this student guide. NADSP has a website and newsletter written by and for DSPs that contains very helpful and supportive information for DSPs. The NADSP website is www.nadsp.org.

Values to Guide Your Work

- This information relates to a learning outcome and may be covered on the quiz.

  Outcome: List the values that guide the DSP's work as outlined in the Lanterman Act.



Show Slide #14: Values of California's Service System for Individuals with Intellectual/Developmental Disabilities

- Read the definition of "values." Judgements about what is important in life. Ideals that shape the quality of services and supports.
- Refer to the slide; these are the values that guide the system that provides services for individuals with intellectual/developmental disabilities in California.

— **Choice**

- Ask students to explain what kinds of choices they are free to make in their own lives. Examples include choosing what kinds of activities in which to participate, what to eat, what to wear, where to live, with whom to be friends, etc.
- Ask students what it means to them to have those kinds of choices.

— **Relationships**

- Ask students to talk about the kinds of relationships they have in their own lives. Examples include family, friends, and significant others.
- Ask students how it feels to them to have close relationships.

— **Regular Lifestyles**

- Ask students why they think it is important for individuals with intellectual/developmental disabilities to be included anywhere that anybody else would be such as work, school, public places and home. Answers might include the idea that exclusion impacts self-esteem and can limit potential.

— **Health and Well-Being**

- Ask students how people get and stay healthy.
- Possible answers include: a healthy diet, regular exercise, medication for special health conditions, health care, appropriate weight, personal care (e.g., bathing, dental and personal hygiene), and avoidance of dangerous or high-risk situations.

Show Slide #15: Choice + Relationships + Regular Lifestyles + Health & Well-Being + Rights & Responsibilities + Satisfaction = A high quality of life.

- All of these values taken together lead to a higher quality of life for individuals and DSPs.

Values to Guide Your Work

The Lanterman Developmental Disabilities Services Act, which became law in the 1970s, established the state's promise to Californians with intellectual/developmental disabilities to provide quality services to meet their individual needs. The Lanterman Act envisions services that reflect the values of individual choice, relationships, regular lifestyles, health and well-being, rights and responsibilities, and satisfaction. Values are ideals that shape the quality of services and supports. Here is what the Lanterman Act says about the value of:

Choice:

Individuals (with help from parents, legal guardians, or conservators when needed) have the right to make decisions about their own lives, such as where and with whom they live, where they work, their relationships with others, the way in which they spend their time, and their goals for the future. Services and supports address the individual's identified needs and respect the individual's preferences. Support may be needed to develop communication and decision making skills.

Relationships:

Individuals with intellectual/developmental disabilities have the right to develop relationships, marry, be a part of a family, and be a parent if they choose.

Support may be needed to help people start and keep relationships with friends and fellow community members or to develop intimate relationships. This support may include services such as transportation, family counseling, or training in human development and sexuality.

Regular Lifestyles:

Individuals have the right to be involved in their community in the same ways as their neighbors, friends, and fellow community members.

Services are provided to the greatest extent possible in the home and community settings where individuals live and work.

Services and supports should meet the cultural preferences of the individual.

Support and training may be needed to help individuals to be as independent and productive as possible.

When an individual's needs change, services should change as well to make sure that the individual can continue living where he or she chooses.

Individuals have the right to be comfortable where they live, have privacy when they need it, and choose the way their living spaces are decorated and arranged.

Services and supports are provided to allow minors with intellectual/developmental disabilities to live with their families to the greatest extent possible.

Health and Well-Being:

Individuals have a right to be free from harm, live a healthy lifestyle, and receive quick medical care and treatment.

Support may be needed to assist individuals to receive medical, mental health, and dental care and treatment when they need it.

Services and supports may be needed to teach individuals how to keep themselves healthy or to seek services and supports that keep them healthy.

Values to Guide Your Work (cont.)

— **Rights and Responsibilities**

- Ask students how they can support individuals to express their rights and responsibilities. Possible answers include:

  Making each individual aware of their rights and responsibilities and ensuring frequent opportunities to use them.
- Rights and responsibilities will be discussed in greater detail in the next session.

— **Satisfaction**

- Ask students to share a personal goal or dream that they have. How will they feel when they accomplish it?
- Explain that everybody, including individuals with intellectual/developmental disabilities, can benefit from the good feeling that comes with making progress toward their goals and dreams.

• The DSP is a key part of the system that provides services for individuals with intellectual/developmental disabilities in California and their work should be consistent with those values.

Rights and Responsibilities:

Individuals with intellectual/ developmental disabilities have the same basic legal rights as other citizens.

Individuals have a right to privacy and confidentiality of personal information.

Individuals have a right to treatment and habilitation; dignity and humane care; education; prompt medical care and treatment; religious freedom; social interaction and participation in community activities; physical exercise and recreation; freedom from harm; freedom from hazardous procedures; and to choices about their lives.

Along with all of these rights are responsibilities, such as respecting the privacy of others and being an informed voter.

Support may be needed for individuals to learn about their rights and responsibilities and how to advocate for themselves.

Satisfaction:

Individuals have the right to plan goals for the future and to work toward them.

Individuals have the right to be satisfied with the services and supports they receive and be supported to change them when they are not satisfied. Individuals have a right to a good quality of life.

Adapted from *Looking at Life Quality*, Department of Developmental Services (1996)

Supporting individuals in having quality of life means supporting them in ways that are consistent with these values: making sure that individuals have choices, spend time with family and friends, have the best possible health, are safe, and are treated with dignity and respect… all the things that are necessary for quality of life.

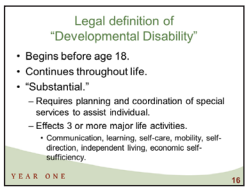
Individuals with Intellectual/Developmental Disabilities

- Individuals that you support are individuals first and foremost.
- Individuals with developmental disabilities can be children, adults, elderly, male or female, and may come from different backgrounds.
- Individuals with developmental disabilities have qualities and preferences that can be unique to them.
- Getting to know each individual is crucial to providing quality care.

What is a Developmental Disability?

- This information relates to a learning outcome and may be covered on the quiz.

  Outcome: Define the term "developmental disability."



Show Slide #16: Legal definition of "Developmental Disability." Read the legal definition of "developmental disability" from the Lanterman Act below

- Share the following information about the nature of the Lanterman Act:
  - — The Lanterman Developmental Disabilities Services Act (Lanterman Act) is that part of California law that sets out the rights and responsibilities of persons with developmental disabilities, and creates the agencies, including regional centers, responsible for planning and coordinating services and supports for persons with developmental disabilities and their families.
  - — Section 4501 of the Lanterman Act states: "The State of California accepts a responsibility for persons with developmental disabilities and an obligation to them which it must discharge. Affecting hundreds of thousands of children and adults directly, and having an important impact on the lives of their families, neighbors and whole communities, developmental disabilities present social, medical, economic and legal problems of extreme importance."
  - — The Lanterman Act defines "developmental disability" as a disability that originates before an individual attains age 18 years, continues, or can be expected to continue, indefinitely, and constitutes a substantial disability for that individual." The Lanterman Act goes on to state, "... this term shall include mental retardation, cerebral palsy, epilepsy, and autism. This term shall also include disabling conditions found to be closely related to mental retardation or to require treatment similar to that required for individuals with mental retardation, but shall not include other handicapping conditions that are solely physical in nature." [Welfare and Institutions Code, Division 4.5 Section 4512(a)]

Causes of a Intellectual/Developmental Disability

Show Slide #17: Causes of Intellectual/Developmental Disabilities

- Summarize the possible causes of developmental disabilities.
- Often the cause of a developmental disability is not known.
- A developmental disability can happen in any family.

Individuals with Intellectual/Developmental Disabilities

Who are the individuals you support? First, they are **people**. The individuals 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 over time. What the individuals you support have in common is that they have developmental disabilities.

Here 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.

What Is a Developmental Disability?

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

- Begins before someone reaches 18 years of age.
- Lasts throughout an individual's life.
- Greatly limits three or more major life activities for the individual.
- Often means there is a need for some kind of assistance in the individual's daily life.

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

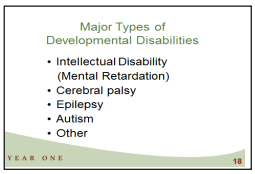
Causes of a Intellectual/Developmental Disability

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 during pregnancy.
- Chemical or chromosomal differences (like Down syndrome) or an inherited condition.
- A lack of oxygen to the brain, low birth weight, or a difficult birth.
- A serious accident, abuse, lead poisoning, or extremely poor nutrition.

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

Show Slide #18: Major Types of Developmental Disabilities



- Read the names of the 5 major types developmental disabilities and have the students repeat them after you.
- One individual may have more than one of these disabilities.
- The information about specific disabilities relates to a learning outcome and may be covered on the quiz.

Outcome: Identify characteristics of specific developmental disabilities.

Intellectual Disability (Mental Retardation)

- Explain to students that the term “intellectual disability” is replacing the term “mental retardation.” They may still hear the term “mental retardation,” but “intellectual disability” is the preferred term.
- Elaborate on the characteristics of intellectual disability in the chart:
  - — Intellectual disability is when a person has significant limitations in intellectual functioning and adaptive skills.
  - — Intellectual functioning includes learning, reasoning and problem solving.
  - — Adaptive skills include understanding abstract concepts (money, time, language and literacy); social skills (interacting with others, following rules and knowing laws, self-esteem); and practical skills (personal care, travel/transportation, schedules/routines, safety, using money, using telephones). Individuals with intellectual disability will learn, but it may take them longer to learn things.
- Explain the different levels of intellectual disability (mild, moderate, severe and profound) and how various levels require different levels of support.
- Inform students of the difference between intellectual disability and mental illness. Some individuals with intellectual disability may also have mental illness.

Cerebral Palsy

- Elaborate on the characteristics of cerebral palsy in the chart:
  - — Cerebral palsy describes a group of chronic conditions affecting body movement and muscle coordination. It is caused by damage to one or more specific areas of the brain, disrupting the brain’s ability to adequately control movement and posture. “Cerebral” refers to the brain and “palsy” to muscle weakness/poor control. Cerebral palsy is not progressive (i.e. brain damage does not get worse); however, secondary conditions, such as muscle spasticity, can develop which may get better, get worse, or remain the same over time. Cerebral palsy is not communicable. It is not a disease and should not be referred to as such. Although cerebral palsy is not “curable” in the accepted sense, training and therapy can help improve function (Adapted from information on the United Cerebral Palsy website: www.ucp.org.).
- Explain the different levels of Cerebral Palsy (mild, moderate, severe and profound) and how individuals with different levels of cerebral palsy may require different levels of support.

Autism

- Elaborate on the characteristics of autism in the chart:
  - — Autism is a complex developmental disability that typically appears during the first two years of life. The result of a neurological disorder that affects the functioning of the brain, autism and its associate behaviors have been estimated to occur in as many as 1 in 68 births (Centers for Disease Control and Prevention, 2012). Autism is almost five times more prevalent in boys (1 in 42) than girls (1 in 189) and knows no racial, ethnic, or social boundaries. Family income, lifestyle, and educational levels do not affect the chance of autism’s occurrence (Adapted from information on the Autism Society website: www.autism-society.org).

(Major Types of Developmental Disabilities - cont. on next page)

Major Types of Developmental Disabilities

The following table lists the major kinds of developmental disabilities: intellectual disability, cerebral palsy, autism and epilepsy. The table also tells you what those disabilities might look like. Keep in mind that some individuals may have one or more of the developmental disabilities listed. Also, a developmental disability is not a contagious disease you can't "catch" it.

Developmental Disability	Characteristics	Notes for the DSP
Intellectual Disability	•Have limitations in learning, reasoning, and problem solving. •Have limitations in conceptual, social, and practical skills. •Thinks about things in more real-life or concrete ways. •Keeps learning and developing throughout life as we all do.	•Level and impact of intellectual disability is different for each individual. This means each individual needs different levels of support and types of service in daily living. •Intellectual disability is very different from mental illness, Some people who have an intellectual disability may have mental illness. •Intellectual disability used to be known as "mental retardation;" you may still hear the term "mental retardation" used.
Cerebral Palsy	•Has involuntary movement. •Has a hard time controlling movement. •Has a hard time maintaining balance or posture. •Has a hard time swallowing or speaking.	•"Cerebral" refers to the brain and "palsy" to muscle weakness or poor control. •There are different levels of cerebral palsy from mild to severe. •There are different types: spastic, athetoid, ataxic, and mixed. •People can lead more independent lives through the use of special devices (for example, computers and wheelchairs). •Physical therapy may help individuals gain more control over movement.
Autism	•Generally has a hard time making friends. •May have unexpected emotional responses, such as laughing at a car accident. •Generally has a hard time communicating with others. •May hurt self (self-injurious). •Generally wants to follow routines and may get upset if things are changed. •May repeat words and/or body movements.	•Affects people in many different ways •The causes are not very well understood.
Epilepsy	•Have seizures which are short surges of electrical activity in the brain. •May "pass out" or become unconscious. •Movement or actions may change for a short time.	•Epilepsy is sometimes called a seizure disorder. •There are different types of seizures and epilepsy syndromes, each looking different and requiring different responses.
Other		•Includes people who need the same kinds of support as those who have an intellectual disability. •Does not include people who only have physical, learning, or mental health challenges. •Examples are conditions like Neurofibromatosis, Tuberous Sclerosis, and Prader-Willi Syndrome.

Epilepsy

- Elaborate on the characteristics of Epilepsy in the chart:
  - — Epilepsy is a neurological condition that makes people susceptible to seizures. A seizure is a change in sensation, awareness, or behavior brought about by a brief surge of electrical activity in the brain. Seizures vary from a momentary disruption of the senses, to short periods of unconsciousness or staring spells, to convulsions. Some people have just one type of seizure. Others have more than one type. Although they look different, all seizures are caused by the same thing: a sudden change in how the cells of the brain send electrical signals to each other. (Adapted from information on the Epilepsy Foundation website: www.epilepsyfoundation.org).
- Some individuals with epilepsy may also have intellectual disability, and/or cerebral palsy, and/or autism.

Other

- What does "Other" mean?
  - — A condition is a "substantial disability" if it is severe enough to be a major impairment of cognitive and/or social functioning (Title 17 § 54001). Substantially disabling conditions require "interdisciplinary planning" and "coordination of services" to help an individual reach their maximum potential.
  - — To determine if a person has a "substantial disability," an assessment is completed to evaluate a wide range of skills, including, at a minimum, communication skills, learning abilities, self-care, mobility, self-direction, independent living skills and economic self-sufficiency. Many tests are available to assess people's abilities in these seven areas and in other day-to-day and long-term functions and abilities (Title 17 § 54001).

Developmental Delays

•Developmental delay is an ongoing, major delay in the process of a child's development. Delay can occur in one or more developmental areas.

Individuals with Intellectual/Developmental Disabilities are People First

- This information relates to a learning outcome and may be covered on the quiz.

  Outcome: Use "People First" language.

Show Slide #19: People First Language

- Refer students to Appendix 1-B: "Examples of People First Language" by Kathie Snow. Highlight the quote by Mark Twain.
  - — Ask students to think back to the video about the Roles of the DSP. When the health club director referred to Jason as "that slow kid," was she using "People First Language?" **No.**
  - — How do you suppose that made Jason feel? **Disrespected, stupid, sad.**
  - — What could the DSP have done? **Played the roles of Advocate and Ambassador, and used the Communication tool. The DSP could have told the health club director in a respectful way that actually Jason has a developmental disability and prefers not to be called "slow." Then the DSP could refocus the conversation to Jason's love of basketball to emphasize that Jason is a person who has preferences and dreams.**

Show Slide #20: Golden Rule vs. Platinum Rule

- Read the definitions.
- This information relates to a learning outcome and may be covered on the quiz.

  Outcome: Define the Platinum Rule.

- Ask the students why they think the Platinum Rule is more appropriate than the Golden Rule.
- Emphasize that individuals are different. We all have different preferences and strengths.
- Ask them ways to find out how others would like to be treated. For example, talk to and observe individuals, and ask their friends and families.

Developmental Delays

An intellectual/ 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 an intellectual/developmental delay can receive early intervention services. These services support the child and their family in learning the things that will help the child start to develop and grow.

Individuals with Intellectual/Developmental Disabilities Are People First

While it's important to learn about the names and causes of developmental disabilities, **individuals with intellectual/ developmental 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 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:

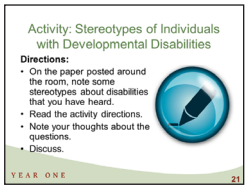
- You take the time to learn about an individual's needs, strengths, and preferences.
- You do not assume that you know what is best.
- Your manner of supporting individuals reflects their needs, strengths, and preferences.

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.

- Golden Rule assumes people want to be treated as you want to be treated.
- All individuals have different preferences and strengths.
- Platinum rule principal states: Let me first understand what the individual wants and then I'll give it to them.

I

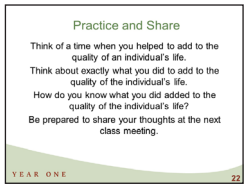
Show Slide #21: Activity: <u>Stereotypes of Individuals with Intellectual/ Developmental Disabilities</u>



- This activity relates to a learning outcomes and may be covered on the quiz.

  Outcome: Discuss your attitudes and beliefs about individuals with disabilities and how those attitudes and beliefs may impact your work.
- Hang four pieces of chart paper around the room. Place markers near each piece of paper.
- Give directions to the students: Go to the paper on the wall closest to you and write down stereotypes that you have heard about individuals with developmental disabilities. It doesn't matter if you write something down that someone else has already written. Don't worry about spelling and grammar.
- Once everyone has had a chance to write something, discuss the activity questions as a class.
- Purpose: To heighten our awareness and keep stereotypes from influencing our perceptions of others as individuals who think and feel – just like us.

Show Slide #22: Practice and Share



- Direct students to the Practice and Share directions.
- Read the directions and make sure students understand the assignment.

A C T I V I T Y

Stereotypes of Individuals with Intellectual/Developmental Disabilities

Directions: *Write down the stereotypes of individuals with intellectual/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 individuals with whom you work if you believe these stereotypes?

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

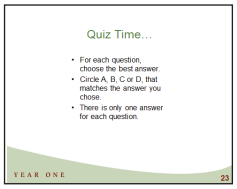
Do you think these stereotypes ever affect the work that DSPs do? If so, how?

How can DSPs overcome these stereotypes?

P R A C T I C E A N D S H A R E

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 the individual's life? How do you know it added to the quality of the individual's life?

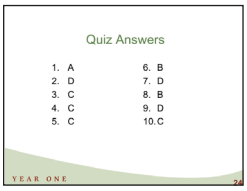
Quiz: The DSP Professional



Show Slide #23: Quiz Time

- Give students 20 minutes to take the quiz.

Show Slide #24: Quiz Answers



- Discuss questions and answers as a class.
- Remind students to mark the correct answers so they can use the corrected quizzes as a study guide for the test after training.

Answers:

1. A
2. D
3. C
4. C
5. C
6. B
7. D
8. B
9. D
10. C

End of Session 1

Session 1 Quiz

The DSP Professional

1. **What is one reason for the DSP Training?**
   A) To help the DSP support individuals to have a better quality of life
   B) To give the DSP more control over the lives of individuals
   C) To make DSPs medical experts
   D) To reduce the amount of work DSPs have to do

2. **One value that guides services in the Lanterman Act is:**
   A) Isolation
   B) Obedience
   C) Dependence
   D) Satisfaction

3. **When a DSP is finding creative and fun ways to help individuals learn meaningful skills, they are playing the role of:**
   A) Ambassador
   B) Boss
   C) Teacher
   D) Parent

4. **Which is an example of "People First" Language?**
   A) Victim of autism
   B) Handicapped person
   C) Individual with a developmental disability
   D) Mentally retarded person

5. **According to California state law, a developmental disability:**
   A) Always begins before someone is born
   B) Goes away with medication and therapy
   C) Greatly limits three or more major life activities
   D) Only includes physical challenges

6. **One characteristic of cerebral palsy is:**
   A) Mental illness
   B) Involuntary movements
   C) High blood pressure
   D) Weak bones

7. **Which DSP tool is used when a DSP looks and listens for things that could affect an individual's health and well-being?**
   A) Documentation
   B) Ethics
   C) Decision Making
   D) Observation

8. **Describe the DSPs role on the individual's planning team:**
   A) The DSP finds and coordinates needed services
   B) The DSP provides services and supports to assist the individual to achieve their goals
   C) The DSP makes decisions for the individual
   D) The DSP assesses the individual's needs and makes recommendations for specific services

9. **What is the Platinum Rule?**
   A) Treat individuals like your friends
   B) Treat others as you would like to be treated
   C) Treat individuals like your own children
   D) Treat others as they would like to be treated

10. **Which Lanterman Act value says that services and supports should be based on an individual's needs and preferences?**
    A) Relationships
    B) Health and well-being
    C) Choice
    D) Rights and responsibilities

Appendices

Appendix 1-A

NADSP Code of Ethics for Direct Support Professionals

The Code of Ethics developed through the National Alliance for Direct Support Professionals (NADSP) guides DSPs through the ethical dilemmas they face daily and encourages the highest professional ideals. Direct support staff, agency leaders, policymakers, and people receiving services are urged to read the code and to consider ways that these ethical statements can be incorporated into daily practice. This code is not the handbook of the profession, but rather a roadmap to assist in staying the course of securing freedom, justice, and equality for all.

1. **Person-Centered Supports.** As a DSP, my first allegiance is to the person I support; all other activities and functions I perform flow from this allegiance.

2. **Promoting Physical and Emotional Well-Being.** As a DSP, I am responsible for supporting the emotional, physical, and personal well-being of the individuals receiving support. I will encourage growth and recognize the autonomy of the individuals receiving support while being attentive and energetic in reducing their risk of harm.

3. **Integrity and Responsibility.** As a DSP, I will support the mission and vitality of my profession to assist people in leading self-directed lives and to foster a spirit of partnership with the people I support, other professionals, and the community.

4. **Confidentiality.** As a DSP, I will safeguard and respect the confidentiality and privacy of the people I support.

5. **Justice, Fairness and Equity.** As a DSP, I will promote and practice justice, fairness, and equity for the people I support and the community as a whole. I will affirm the human rights, civil rights and responsibilities of the people I support.

6. **Respect.** As a DSP, I will respect the human dignity and uniqueness of the people I support. I will recognize each person I support as valuable and help others understand their value.

7. **Relationships.** As a DSP, I will assist the people I support to develop and maintain relationships.

8. **Self-Determination.** As a DSP, I will assist the people I support to direct the course of their own lives.

9. **Advocacy.** As a DSP, I will advocate with the people I support for justice, inclusion, and full community participation.

Appendix 1-B

Examples of People First Language

by Kathie Snow: www.disabilityisnatural.com to see the complete article

Remember: a disability descriptor is simply a medical diagnosis:
People First Language respectfully puts the person before the disability:
and a person with a disability is more like people without disabilities than different!

SAY:	INSTEAD OF:
People with disabilities.	The handicapped or disabled.
He has a cognitive disability/diagnosis.	He's mentally retarded.
She has autism (or diagnosis of…).	She's autistic.
He has Down syndrome (or diagnosis of…).	He's Down's; a mongoloid.
She has a learning disability (or diagnosis of…).	She's learning disabled.
He has a physical disability (diagnosis).	He's quadriplegic/is crippled.
She's of short stature/she's a little person.	She's a dwarf/midget.
He has a mental health condition/diagnosis.	He's emotionally disturbed/mentally ill.
She uses a wheelchair/mobility chair.	She's confined to/is wheelchair bound.
He receives special ed services.	He's in special ed.
She has a developmental delay.	She's developmentally delayed.
Children without disabilities.	Normal or healthy kids.
Communicates with her eyes/device/etc.	Is nonverbal.
Customer	Client, consumer, recipient, etc.
Congenital disability	Birth defect
Brain injury	Brain damaged
Accessible parking, hotel room, etc.	Handicapped parking, hotel room, etc.
She needs... or she uses...	She has problems with... has special needs.

Keep thinking-there are many other descriptors we need to change!

Excerpted from Kathie's People First Language article, available at www.disabilityisnatural.com.

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