



Student Resource Guide

1. The Direct Support Professional



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 DSP’s 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

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 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?

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 Direct Support Professional's (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?

Introduction

What is the purpose for this 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 developmental disabilities, which will lead to a better quality of life

for them. 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? As we discussed in the Introduction to this training, 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 and are safe.
- ▶ Are treated with dignity and respect.
- ▶ Are satisfied with their lives.

ACTIVITY

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. _____

DSP Training for a Better Quality of Life

Now let's see what some individuals with developmental disabilities have to say about what quality of life means to them. In 2003, 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



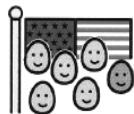
to live

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

DSP Training for 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 to make 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 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

A Direct Support Professional (DSP) works with and supports individuals with developmental disabilities in the places they live and work. DSPs perform their jobs in licensed homes, day programs, supported or independent living environments, or 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 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 hope and dream about. 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, or conservators, as appropriate, make decisions about their own lives.

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.

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 | • 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. |
| Teacher | • Tom helped A.J. with his medication. |
| Ambassador | • Tom spent time teaching A.J. how to put a DVD into his own DVD player. |
| Advocate | • Tom helped A.J. and Marissa make breakfast. |
| Supporter | • 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. |

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. NADSP has a Web site and newsletter written by and for DSPs that contains very helpful and supportive information for DSPs.

Values to Guide Your Work

The Lanterman Developmental Disabilities Services Act, which became law in the 1970s, establishes the state's promise to Californians with 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 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 the life of 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 be changed 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 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 (continued)

Rights and Responsibilities:

Individuals with 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 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 the 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 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 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 a 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.

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.

<i>Developmental Disability</i>	<i>Characteristics</i>	<i>Notes for the DSP</i>
Intellectual Disability	<ul style="list-style-type: none"> • Has limitations in learning, reasoning, and problem solving. • Has 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. 	<ul style="list-style-type: none"> • Level and impact of intellectual disability are different for different individuals. This means that individuals need different levels of support and types of services in daily living. • Intellectual disability is very different from mental illness. Some people who have intellectual disability also have mental illness, but most do not. • Intellectual disability used to be known as 'mental retardation'; you may still here the term 'mental retardation' used.
Cerebral Palsy	<ul style="list-style-type: none"> • Has involuntary movement. • Has a hard time controlling movement. • Has a hard time maintaining balance or posture. • Has a hard time swallowing or speaking. 	<ul style="list-style-type: none"> • "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 to gain more control over movement.
Autism	<ul style="list-style-type: none"> • 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 other people. • May hurt self (self-injurious). • Generally wants to follow routines and may get upset if things get changed. • 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.
Epilepsy	<ul style="list-style-type: none"> • Has 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. 	<ul style="list-style-type: none"> • Epilepsy is sometimes called a seizure disorder. • There are different types of seizures and epilepsy syndromes, each looking different and requiring different responses.
Other		<ul style="list-style-type: none"> • Includes people who need the same kinds of support as those who have mental retardation. • Does not include people who have only physical, learning, or mental health challenges. • Examples are conditions like Neurofibromatosis, Tuberous Sclerosis, and Prader-Willi Syndrome.

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 tod-

dlers who have a 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 Developmental Disabilities Are People First

While it’s important to learn about the names and causes of developmental disabilities, **individuals with 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.

ACTIVITY

Stereotypes of Individuals with Developmental Disabilities

Directions: Write down the stereotypes of individuals with 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?

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

Session 1 Quiz

The DSP Profession

1	<input type="checkbox"/> A	<input type="checkbox"/> B	<input type="checkbox"/> C	<input type="checkbox"/> D
2	<input type="checkbox"/> A	<input type="checkbox"/> B	<input type="checkbox"/> C	<input type="checkbox"/> D
3	<input type="checkbox"/> A	<input type="checkbox"/> B	<input type="checkbox"/> C	<input type="checkbox"/> D
4	<input type="checkbox"/> A	<input type="checkbox"/> B	<input type="checkbox"/> C	<input type="checkbox"/> D
5	<input type="checkbox"/> A	<input type="checkbox"/> B	<input type="checkbox"/> C	<input type="checkbox"/> D
6	<input type="checkbox"/> A	<input type="checkbox"/> B	<input type="checkbox"/> C	<input type="checkbox"/> D
7	<input type="checkbox"/> A	<input type="checkbox"/> B	<input type="checkbox"/> C	<input type="checkbox"/> D
8	<input type="checkbox"/> A	<input type="checkbox"/> B	<input type="checkbox"/> C	<input type="checkbox"/> D
9	<input type="checkbox"/> A	<input type="checkbox"/> B	<input type="checkbox"/> C	<input type="checkbox"/> D
10	<input type="checkbox"/> A	<input type="checkbox"/> B	<input type="checkbox"/> C	<input type="checkbox"/> D

- 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) an ambassador.
 - B) a boss.
 - C) a teacher.
 - D) a 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. When you see  in the Student Resource Guide, it tells you to use this DSP tool:
- A) Communication
 - B) Ethics
 - C) Observation
 - D) Decision making
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

EXAMPLES OF PEOPLE FIRST LANGUAGE

BY **KATHIE SNOW**; VISIT 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 a diagnosis of...).	She's autistic.
He has Down syndrome (or a diagnosis of...).	He's Down's; a mongoloid.
She has a learning disability (diagnosis).	She's learning disabled.
He has a physical disability (diagnosis).	He's a 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 non-verbal.
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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