



Trainer Resource Guide

2. The California Developmental Disabilities Service System



Trainer Guide: SESSION 2

Materials

- LCD projector and computer
- Flash Drive
- DSP TV DVD, Year 1

Show Slide #1: The California Developmental Disabilities Service System



Show Slide #2: Practice and Share, Session 1

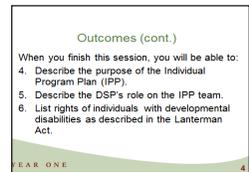
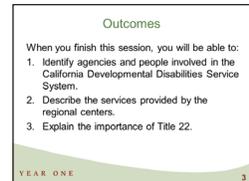
- In the last session, you learned about the values that guide your work as a DSP. In this session, you will learn about the system for coordinating and planning services and supports for individuals with intellectual/developmental disabilities in California.



Outcomes

Show Slides #3 and #4: Outcomes

- Review outcomes for the session.



Key Words

Show Slides #5, #6, and #7: Key Words

- Give students 5 minutes to think about and rewrite definitions in their own words in the spaces provided.



The California Developmental Disabilities Service System

OUTCOMES

When you finish this session you will be able to:

- Identify agencies and people involved in the California developmental disabilities service system.
- Describe the services provided by the regional centers.
- Explain the importance of Title 22.
- Describe the purpose of the Individual Program Plan (IPP).
- Describe the DSP's role on the individual's planning team.
- List rights of individuals with developmental disabilities as described in the Lanterman Act.

KEY WORDS

Key Word	Meaning	In My Own Words
Community Care Facilities	Homes operated by people or agencies who are granted a license by the State of California to provide residential care.	
Confidentiality	Keeping information about an individual private; sharing information about an individual only with permission to do so.	
Denial of Rights	Process where a right may be taken away for a limited period of time, for a specific reason, and only under certain conditions which are documented and approved by the regional center.	
Goal	Things described in an Individual Program Plan that the individual wants in his or her future; goals reflect the individual's needs and preferences.	

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Key Words - cont.

Key Words (continued)

- **Individual's Rights**
 - Right to be treated like everyone else.
- **Legally Authorized Representative**
 - Parent, guardian or conservator.
- **Person-Centered**
 - Based on the needs, preferences and choices of the individual.
- **Planning Team**
 - Individual, legally authorized representative and service coordinator.
- **Preferences**
 - Choices

YEAR ONE 6

KEY WORDS (CONT.)

Key Word	Meaning	In My Own Words
Individual Program Plan (IPP)	A written agreement, required by the Lanterman Act, between the individual and the regional center. The IPP lists the individual's goals and the services and supports needed to reach those goals.	
Individual's Rights	Specific rights, granted by the Lanterman Act to individuals who are developmentally disabled to ensure that they are treated like everyone else; for example, the right to dignity and humane care.	
Legally Authorized Representative	Parent(s) or legally appointed guardian of a minor child, or legally appointed conservator of an adult.	
Person-Centered	Based on the needs, preferences, and choices of the individual with the developmental disability.	
Planning Team	A group of people who come together to plan for and support the needs and preferences of the individual. The planning team must include the individual, the legally authorized representative (parent of a minor, guardian of a minor, or conservator of an adult) if applicable, and the regional center service coordinator.	
Preferences	Choices that the individual makes.	
Regional Center	One of 21 centers created by the Lanterman Act and located throughout California. Regional centers assist individuals with developmental disabilities and their families to find and access services.	
Service Coordinator	A regional center representative who works with individuals and families to find and organize access to needed services and supports.	

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Key Words - cont.

Key Words (continued)

- **Regional Center**
 - Assists individuals with developmental disabilities to receive services and supports.
- **Service Coordinator**
 - Regional center representative who organizes access to services and supports.
- **Services and Supports**
 - Assistance provided to support an individual's quality of life.
- **Title 17**
 - Rules for regional centers and their vendors.
- **Title 22**
 - Rules for licensed community care homes.

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KEY WORDS (CONT.)

Key Word	Meaning	In My Own Words
Services and Supports	Assistance provided for the individual to lead the most independent and productive life possible, based on the individual's needs, goals, and preferences.	
Title 17	Rules for regional centers and regional center vendors including vendored community care facilities.	
Title 22	Rules for licensed community care facilities.	

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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.

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 developmental disabilities service system in California?

.....

What do you **want to know** about about the developmental disabilities service system in California?

.....

To be answered at the end of the session, during review:
What **have you learned** about about the developmental disabilities service system in California?

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California Developmental Disabilities Service System

- Review the information in the Student Guide. Provide additional history and background on the Lanterman Act that may assist students in understanding the need for this legislation in California.
 - In the 1960s, California's state hospitals housed 13,500 people with mental illness or developmental disabilities. People in state hospitals were often abused, stripped and tied to gurneys, sterilized and locked in isolation rooms. There were horrifying reports in newspaper investigations and a well-chronicled visit by a famous Danish doctor who said that in his country, cattle were treated better than the women with developmental disabilities he saw at a Developmental Center.
 - A small yet powerful group of parents decided to change the system for people with developmental disabilities in California. After many years of struggle they succeeded in making the Lanterman Developmental Disabilities Services Act a reality. The Lanterman Act provides the entitlement program in California for people with mental retardation, cerebral palsy, epilepsy and autism, and established the Regional Center system to carry out these state mandates.

Note to trainer: If you have an internet connection, the video 'A Credo for Support' by Norm Kunc and Emma van der Klift is a powerful tool for relaying the above information. You may access the video at: <http://www.normemma.com/videos/credo.htm>

Show Slide #8: California Developmental Disabilities Service System

Review each of the agencies and organizations and summarize what they do.

- This information relates to a learning outcome and may be covered on the quiz.
Outcome: Identify agencies and people involved in the California Developmental Disabilities Service System.



Show Slide #9: Department of Developmental Services (DDS)

- This information relates to a learning outcome and may be covered on the quiz.
Outcome: Describe the services provided by the regional centers.
- Regional centers may purchase many different types of services to meet individual needs. Among these services are:
 - Early intervention services
 - Health-related services
 - In-home support services
 - Day and vocational services
 - Residential services



California Developmental Disabilities Service System

The California State Legislature passed the Lanterman Act to create a network of agencies responsible for planning and coordinating services and supports for individuals with developmental disabilities and their families.

The developmental disabilities service system includes the following agencies and organizations:

- Department of Developmental Services (DDS)
 - Regional centers
 - Regional center vendors
- State Council on Developmental Disabilities (SCDD)
- Developmental Disabilities Area Boards
- Disability Rights California (DRC)

DDS provides leadership, oversight, coordination, and funding for regional centers. DDS writes regulations or rules for regional centers and regional center vendors. These regulations are typically referred to as Title 17. You need to be familiar with Title 17 because it describes rules and requirements for how you do your job. [Information about how to get a copy of Title 17 is included in Appendix 2-A.

The Lanterman Act created 21 regional centers located throughout the state. **Regional centers** evaluate the needs of individuals to determine if they qualify, or are eligible to, receive services. You may hear this process referred to as ‘determining eligibility.’ A variety of services may be provided to eligible individuals and their families including assessment, advocacy, planning, purchase of services from vendored (contracted) service providers, and service coordination.

A **service coordinator** organizes the activities necessary to create and implement an **Individual Program Plan (IPP)** for each person served by the regional center.

The Individual Program Plan is developed by the individual and his or her planning team. The IPP lists the goals that a person is trying to achieve and describes a plan for achieving those goals. The regional center may purchase a service directly or assist the individual to access generic services (services that are used by everyone in the community).

Regional centers may purchase many different types of services to meet individual needs. Services may include:

- Early intervention services—Infant development programs, and preschools.
- Health-related services—Assessment and consultation from doctors and other health care professionals as needed.
- In-home support services—Respite and family support.
- Day and vocational services—Day program services, independent living services, habilitation services, supported employment, and work activity programs.
- Residential services—Supported living services, adult family home services, and community care facilities.

Many different agencies and individuals are vendored (or contracted) with regional centers to provide these services. The community care facility in which you work is one of about 5,700 licensed community care facilities vendored with the regional centers to provide residential services in the state of California.

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The Developmental Service System Pyramid

Show Slide #10: The Developmental Service System Pyramid

- It is helpful to think of the system as a pyramid with the Lanterman Act as the foundation and various levels of support for the individual above that.
- Individuals are at the top of the pyramid because they have a central role in the system, and have leadership in the design of services and supports to meet their needs.
- Discuss each part of the pyramid and that agency's role in supporting individuals with intellectual/developmental disabilities.



California Developmental Disabilities Service System (cont.)

Regional centers have a responsibility to ensure the quality of services provided by vendors to individuals. The Lanterman Act requires regional centers to make at least two unannounced visits a year to vendored **community care facilities**—the places where you work—and to regularly monitor services to ensure they are of good quality and that individuals and their families are satisfied.

The Lanterman Act also provides for advocacy through the State Council on Developmental Disabilities, Developmental Disabilities Area Boards, Disability Rights California, and Protection and Advocacy. All have a responsibility to advocate on behalf of individuals with intellectual/developmental disabilities and

their families to ensure that their service needs are being met, that services are of good quality, and that rights are being respected.

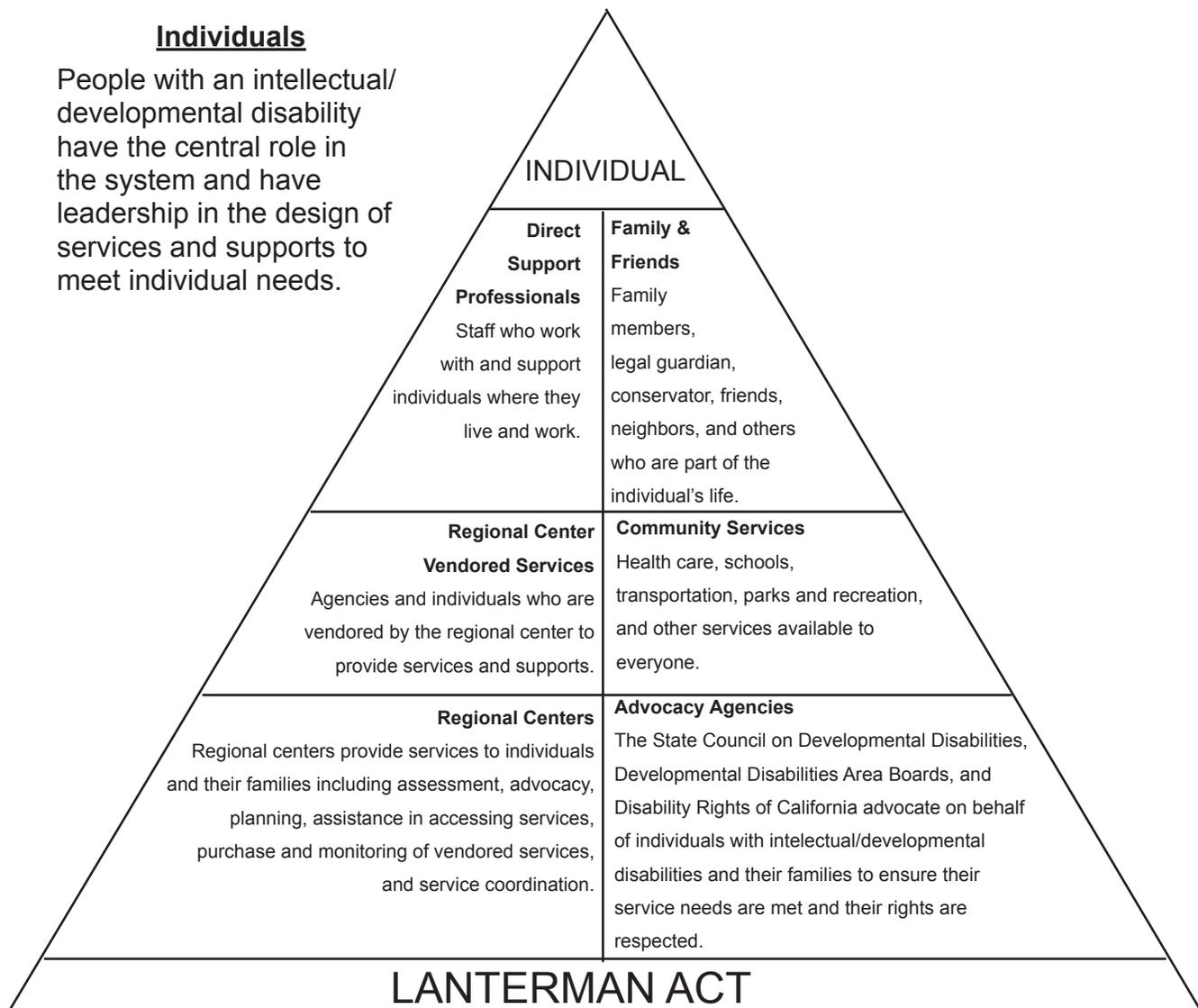
There is a whole network of people and agencies that are working to support individuals and their families in addition to DSPs. These agencies and individuals make up the developmental disabilities service system in California, and all have a common goal of ensuring quality services to support individuals to have healthy, safe, and fulfilling lives.

It is helpful to think about this system of services as a pyramid with the Lanterman Act as the foundation and various levels of support for the individual building upon that foundation.

The Developmental Service System Pyramid

Individuals

People with an intellectual/developmental disability have the central role in the system and have leadership in the design of services and supports to meet individual needs.



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Department of Social Services, Community Care Licensing

Show Slide #11: Department of Social Services, Community Care Licensing (CCL)

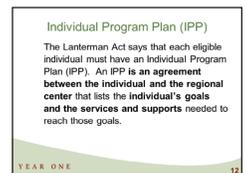
- This information relates to a learning outcome and may be covered on the quiz.
Outcome: Explain the importance of Title 22.
- Homes where DSPs work are both licensed by CCL and vendored by regional centers.



Individual Program Plan

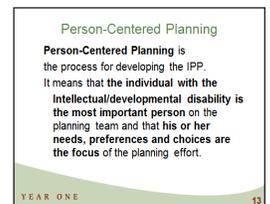
Show Slide #12: Individual Program Plan (IPP)

- Review the statement on the slide and the information in the Student Guide.
- This information relates to a learning outcome and may be covered on the quiz.
Outcome: Describe the purpose of the Individual Program Plan (IPP).
- The IPP is developed by a planning team. An individual's planning team is made up of at least the individual, their authorized representative if they have one, their parents, their conservator or guardian, if appropriate, anyone else they want to have at the meeting, and one or more representatives of the regional center, including the service coordinator or social worker (WIC § 4512(j)).
- Examples of IPP goals include:
 - Make friends and develop relationships with peers
 - Go to school and/or have a job
 - Live in the community
 - Make decisions about where, with whom, and how they want to live
 - Learn skills such as handling their money, cooking, and using the bus
 - Identify additional support needs of the person and their family, such as respite, day care, and behavior services



Show Slide #13: Person-Centered Planning

- Review the definition.
- Person-centered planning is an approach to working toward individuals' preferred future. It gives them a way to say where and with whom they want to live, how and with whom they want to spend their time, where they want to work, and how they want to arrange other important parts of their life (WIC § 4512(j)). Person-centered planning is an ongoing process, not just one meeting.
- The service coordinator will talk to the individual in order to monitor the implementation of the IPP at least once every three months.



Department of Social Services, Community Care Licensing

As a DSP working in a community care facility, you also need to know about Community Care Licensing (CCL). The Department of Social Services (DSS) is a state department that licenses homes for children, adults, and the elderly through its CCL Division. DSS writes regulations or rules for community care licensed facilities. These regulations are typically referred to as **Title 22**. You need to be familiar with Title 22 because it explains how you do your job. (Information about how to get a copy of Title 22 is included in Appendix 2-A.)

Community Care Licensing has a responsibility to monitor homes to ensure that they follow the requirements contained in Title 22 licensing regulations. CCL facility evaluators visit homes on at least a yearly basis to make sure that services are being provided as required in Title 22.

The Individual Program Plan

The Lanterman Act says that each eligible individual must have an **Individual Program Plan (IPP)**. The IPP is a written agreement between the individual and the regional center that lists the individual's goals and the services and supports needed to reach those goals. The IPP is developed by the planning team based upon the individual's needs and preferences.

The IPP is developed through a process of **person-centered planning**. This means that the individual with the intellectual/developmental disability is the most important person on the **planning team** and that his or her needs, preferences, and choices are the focus of the planning effort. The regional center must provide information that supports individuals as they make choices about the services and supports they need.

The IPP contains goals, objectives, and plans. **Goals** describe things that the individual wants in his or her future. **Objectives** set a time frame for achieving the goals. **Plans** are the steps to achieve the goal and describe who will do what and by when. As a DSP, you are often responsible for providing services and supports to assist the individual to achieve his or her IPP goals.

Once services and supports are agreed upon, the regional center must help find the services the individual needs. The regional center service coordinator works with individuals and the IPP team to locate and organize needed services and supports. At least once every three months, the service coordinator will visit the individual, usually at his or her home, to talk to the individual and to monitor the implementation of the IPP.

IPPs also contain a review date, an agreed-upon time (but no less than yearly) when goals, objectives, and plans will be looked at by the planning team to determine progress toward goals.

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The Individual Program Plan (cont.)

Show Slide #14: DSPs Role in the IPP Process

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

Outcome: Describe the DSP's role on the IPP team.

Show Slide #15: DSP TV video, Scene 3: Using the IPP

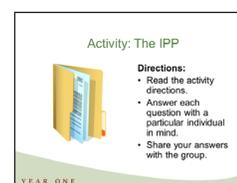
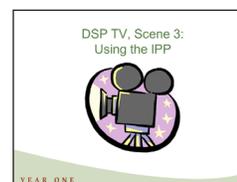
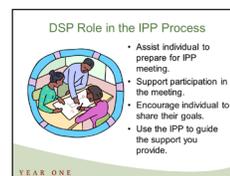
- Read and discuss questions at end of Scene 3.

Answers:

- What mistakes did you observe? **The DSP gave Kwan tomatoes for lunch, didn't give Kwan her adaptive spoon, turned off her Disney movie, disregarded her request for her bird, and left her in the sun for an hour without a hat or sunscreen.**
- What are possible consequences? **Kwan could have an allergic reaction to the tomato that could, at the very least, make her sick and, at the most, prove fatal. Kwan could also sustain a serious sunburn or heat stroke. In addition, Kwan's quality of life is lessened because she is deprived of the things she enjoys. By extension, the DSP's professional life could be much more challenging if some or all of these things were to happen.**
- What could the DSP do differently? **Read Kwan's IPP and tailor her support accordingly.**

Show Slide # 16: Activity: The IPP

- Read the directions aloud.
- Ask for volunteers to share their answers to the activity questions.



The Individual Program Plan (cont.)

The DSP's role is to follow the directions in the IPP about how to support the individual to meet his or her daily needs and to achieve his or her goals. You may assist the individual to get ready

for his or her IPP meeting. You can do this by talking to the individual about what he wants in his life, his hopes and dreams, and by encouraging him to share his thoughts with the planning team.

ACTIVITY

The IPP

Directions: *Think about an individual you work with. With a partner, take turns asking each other the following questions about the individuals you each work with. If there are questions you couldn't answer, go back to the home where you work, read the individual's IPP and try to find the answers.*

1. Where is the individual's IPP located?
2. What does that IPP require you and other staff in the home do for the individual?
3. How do you know, or learn about, his/her likes and dislikes?
4. Name some of his/her likes or dislikes.
5. How do you make sure that the services you provide meet his/her needs and preferences?
6. How do you know when the needs or preferences of the individual change?
7. What do you do when you observe such a change?
8. What kinds of input are you asked to give when it is time to develop or change the individual's IPP?

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Individual Rights

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

Outcome: List rights of individuals with developmental disabilities as described in the Lanterman Act.

Show Slide #17: What the Lanterman Act says about individual rights

- Read the statement from the Lanterman Act:
 - “...persons with developmental disabilities have the same legal rights and responsibilities guaranteed all other individuals by the United State Constitution and laws and the Constitution and laws of the State of California. An otherwise qualified person by reason of having a developmental disability shall be excluded from participation in, be denied the benefits of, or be subjected to discrimination under any program or activity which receives public funds” (WIC § 4502).
 - Since these rights are frequently denied and there is no effective method of implementation, a State Council on Developmental Disabilities was created (WIC § 4520).
- Review information about specific rights under the bold headings in the Student Guide.



Show Slide #18: “Confidential” means...

- Discuss issue of “confidentiality.”
- Continue to review the information under bold headings in the Student Guide.
- HIPPA provides federal protections for personal health information.
- HIPPA gives patients an array of rights with respect to that information.



Individual Rights

The Lanterman Act says that individuals with developmental disabilities have the same rights as everyone else. The Lanterman Act says that individuals have:

A right to services and supports to help them live the most independent productive life possible.

DSPs and others must support individuals to meet their goals in the following areas:

- Where to live
- Where to go to school
- Where to work
- How to become involved in community activities
- Who to live and have relationships with
- What services and supports the individual wants and needs

A right to dignity and humane care.

The DSP must treat individuals with respect and as valued members of society. The DSP must work to ensure that the individual has a safe, comfortable, and caring environment with a right to privacy. The DSP must respect the individual's privacy in all areas including:

- Personal care
- Mail and telephone conversations
- Time to be with family or friends
- Personal (alone) time
- Personal space (in the individual's room)
- Personal possessions
- Sexual expression

In addition, the DSP must not share personal information about an individual except as required as a part of your job. Information about the individual is confidential.

Confidential means you:

- Do not discuss information about individuals with your friends.
- Do not take individuals' records out of the home.
- Do not give information to persons who ask for it without a signed consent from the individual or legally authorized representative.
- Do not discuss confidential information with another individual living in the facility.

A right to participate in an appropriate program of public education.

Public schools must provide an education to individuals younger than 22 years of age. For children of school age, DSPs must work with local schools to support each child's educational program.

A right to prompt medical care and treatment.

Staying as healthy as possible is important for everyone. People should have access to care to achieve the best possible health. The DSP's role is to help individuals get medical, mental health, and dental care and treatment. This means knowing about each person's health care needs, preparing for a doctor's visit, getting to the doctor, assisting with the use of medical insurance, and getting emergency medical help when necessary.

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Individual Rights (cont.)

- Review the information under each bold heading in the Student Guide.

Individual Rights (cont.)

A right to religious freedom and practice.

Many individuals belong to religious communities and go to services at a church, temple, mosque, or other meeting place, to be with people who believe the same things and worship the same way. The DSP's role is to support the individual by helping them with transportation or whatever else may be necessary to enable the individual to practice his or her beliefs. Individuals who are developmentally disabled have the right to believe what they want about religion or faith. The DSP cannot:

- Tell the individual what to believe.
- Punish the individual for what he or she believes.
- Stop the individual from becoming a member of or practicing a religion of his or her choice.

A right to social interaction and participation in community activities.

Everyone likes to have friends and to do fun things with their friends. The DSP's role is to support individuals to:

- Choose the people they spend time with.
- Spend time with people they like and who like them.
- Choose where they want to go in their free time.
- Go to places where they can work, take care of personal business, buy things, help other people, learn things, and meet and be with other people.

A right to physical exercise and recreation.

Exercise helps individuals keep their bodies strong and healthy. Walking, biking, running, swimming, and going to the gym are types of physical exercise. Recreational activities help individuals relax and have fun. They may include such activities as playing music, biking,

swimming, and dancing. The DSP's role is to assist the individual to participate in activities of their choice and to do things they want to do for fun or relaxation.

A right to be free from harm.

Individuals cannot be secluded or restrained in any way. Individuals should have a chance to learn how to keep themselves safe, or have services and supports that provide safety.

No one is allowed to:

- Refuse to help individuals who need help to eat, go to the bathroom, or stay clean and well-groomed. This is called neglect.
- Hit, push, or hurt an individual in any way. This is called abuse.
- Scare an individual.
- Stop an individual from talking.
- Stop an individual from going somewhere important to him or her.
- Give an individual medicine when he or she does not need or want it.
- In any way abuse an individual or neglect his or her care.

If the DSP sees that an individual is abused or neglected, the DSP is mandated to report it. [Mandated reporting will be covered in detail in the next session.]

A right to be free from hazardous procedures.

Doctors and other professionals sometimes do things to figure out why an individual is having problems so they can help them. These "things" are called "procedures." Some procedures may hurt, but they are necessary. Procedures that hurt an individual unnecessarily or harm other parts of his or her body or mind are called "hazardous" procedures. An example of a hazardous procedure is using electric shock to change the individual's behavior.

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Individual Rights (cont.)

- Review the information under each bold heading in the Student Guide, including what the Lanterman Act states concerning the personal rights of individuals who live in licensed residential facilities.

Individual Rights (cont.)

A right to get services and supports in the “least restrictive environment.”

“Least restrictive environment” means places close to the individual’s home community, including places where people without disabilities get services and supports, if that is appropriate. This also means services should be near the individual’s home and with people from his or her community.

A right to make choices about:

- Where and with whom they live.
- Relationships with others.
- How they spend their time.
- Goals for the future.
- Services and supports they want and need.

The DSP’s role is to support these choices, to ensure opportunities for individuals to make choices in their daily lives, and to respect and honor the individuals’ choices.

A right to have friends and intimate relationships, marry, be part of a family, and to be a parent if they choose.

The DSP’s support may be needed to help people start and keep relationships with friends and other community members. The DSP is also responsible to support individuals in obtaining accurate information about human sexuality to assist individuals in their life choices. Support may be needed to develop intimate relationships (like transportation, family counseling, or training in human development and sexuality). Individuals have a right to sexual expression and to information about—and to choose or refuse—birth control options.

A right to be involved in their community in the same way as their neighbors, friends, and fellow community members.

DSPs must find ways to honor cultural preferences for foods, celebrations of holidays, involvement in organizations, and other activities the individual may choose. DSPs must also support individuals in participating as members of their communities and help to create supportive and welcoming communities.

The Lanterman Act also states that individuals who live in licensed residential facilities have these personal rights:

- To wear their own clothes.
- To keep and use their own personal possessions, including toiletries or other personal care items.
- To keep and be allowed to spend a reasonable sum of their own money.
- To have access to individual storage space for private use.
- To see visitors each day.
- To have reasonable access to telephones, and to make and receive confidential calls.
- To have ready access to letter writing materials, including stamps, and to mail and receive unopened correspondence.
- To refuse electroconvulsive therapy.
- To refuse behavior modification techniques that cause pain or trauma.
- To refuse psychosurgery.
- To make choices in areas including, but not limited to, daily living routines, companions, leisure and social activities, and program planning and implementation.
- To have information needed to make an informed choice.

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Legally Authorized Representatives

Show Slide #19: Legally Authorized Representatives

- Review information in the Student Guide.
- Summarize “Competence” paragraph.



Show Slide # 20: Conservatorships

- Review information in the Student Guide.



Legally Authorized Representatives

Parents, Guardians, and Conservators

As a DSP, you need to have a basic understanding of the rights and responsibilities of parents and other **legally authorized representatives**. A parent or guardian of a minor (child under the age of 18) or, under certain circumstances, the conservator of an adult (18 years or older) may make decisions for the individual. Some of those decisions may affect the individual's rights.

Competence

Competence (or incompetence) refers to an individual's ability to make decisions. Children (in California, a child is anyone under age 18) are presumed to be incompetent, that is, not able to manage alone to come to reasoned decisions about certain important matters. Upon reaching adulthood (in California, anyone 18 or older), even if the person has a significant intellectual impairment, he or she is presumed to be competent and able to make decisions on his or her own.

Parents

Parents are considered natural guardians of their biological or adopted children (under 18 years of age) and have certain rights and responsibilities in making decisions on behalf of their children.

Some parents incorrectly presume that as parents, their legal responsibilities continue for their adult child with an intellectual/developmental disability. This is not true unless there has been court action to declare an adult "incompetent."

Guardianship

Some children (under 18) need a court-appointed guardian if parents have died, abandoned a child, or had their parental rights removed by a court of law. The issues surrounding guardianship are few, precisely because the law presumes incompetence. Since 1981, guardianships have only been available for minors.

Conservatorship

A conservatorship is a legal arrangement in which a competent adult oversees the personal care or financial matters of another adult considered incapable of managing alone. There are two kinds of conservatorship:

General Conservatorship

This is the conventional kind of conservatorship for incapacitated adults unable to meet their own needs or manage their own affairs.

Limited Conservatorship

The purpose of limited conservatorship is to protect adults with intellectual/developmental disabilities from harm or exploitation while allowing for the development of maximum self-reliance. If granted by the court, the limited conservator can have decision making authority (or be denied authority) in as many as seven areas:

- To choose and secure the person's place of residence.
- To access confidential records and papers.
- To consent or withhold consent to marriage.
- The right to contract.
- The power to give or withhold medical consent.
- Decisions regarding social and sexual contacts and relations.
- Decisions concerning education or training.

Short of a special court order, the limited conservator may not, however, provide substitute consent in the areas of:

- Experimental drug treatment
- Electroshock therapy
- Placement in a locked facility
- Sterilization

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Legally Authorized Representatives (cont.)

Denial of Rights

Show Slide #21: Denial of Rights

- Review information in the Student Guide.



Legally Authorized Representatives (cont.)

The limited conservator should have:

- Personal knowledge of the conserved individual.
- Knowledge of what constitutes the “best interest” of the conserved individual.
- A commitment to providing that which is in the person’s “best interest.”
- Financial management skills (as appropriate).
- A knowledge of programs and services and their availability and effect.
- Knowledge of appropriate methods of protection.
- Proximity to the conserved individual.
- Availability in terms of time and energy.

Denial of Rights

Most individual rights may not be denied for any reason. Some personal rights of individuals living in licensed homes may be denied for a limited period of time under a very narrow set of circumstances. This is called the **Denial of Rights for “Good Cause.”** **The individual’s rights may be denied only when certain conditions are documented, and the denial is approved by the regional center.**

Only the following rights may be denied for good cause:

- To keep and be allowed to spend one’s own money for personal and incidental needs.
- To keep and wear one’s own clothing,
- To keep and use one’s own personal possessions.
- To have access to individual storage space for one’s private use.
- To see visitors each day.
- To have reasonable access to telephones, both to make and receive confidential calls.
- To mail and receive unopened correspondence and to have ready access to letter writing materials, including U.S. postage stamps.

No other right may be denied unless authorized by the court system.

“Good cause” for denying an individual’s rights is present only when the facility manager finds that:

- (a) Exercising a specific right might injure the individual; or
- (b) Exercising a specific right would seriously infringe on the rights of others; or
- (c) The facility would be seriously physically damaged if the specific right were not denied; **and**,
- (d) There is no less restrictive way to protect the individual, the rights of others, or the facility.

A right may not be denied as a punishment or considered a privilege to be earned. If any rights are denied for good cause, the individual has the right to appeal the denial or to refuse to submit to the denial and leave the facility. (WIC § 4503 & 4504)

Trainer Guide: SESSION 2

Prevention and Problem Solving Rights “Issues”

Show Slide #22: Prevention and Problem Solving Rights “Issues”

- Review information in the Student Guide.



Show Slide #23: DSP TV video, Scene 4: Supporting Rights

- Read and discuss questions at end of Scene 4.

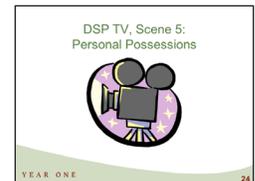
Answers:

- Why should A.J. understand his rights? ***If AJ knows his rights, it is likely that he will feel a greater sense of control over his life and that his rights will not be violated.***
- What did Mike do to help? ***He made AJ aware of his rights, explained them in a way that AJ could understand, and allowed AJ to choose when to learn about his rights.***
- What can you do in your home (to make individuals aware of their rights)? ***Post a copy of individual's rights in the home, remind individuals about their rights during daily routines, encourage and assist individuals to advocate for themselves, and consider developing house rules that reflect the concerns and preferences of individuals living in the home.***



Show Slide #24: DSP TV video, Scene 5: Personal Possessions

- Click on the icon to show the video.
- Read and discuss questions at end of Scene 5.



Answers:

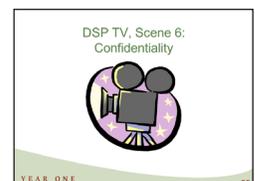
- What is the rights issue? ***Individuals have a right to have personal possessions and to make choices about whether and when to lend them to other people.***
- Did Mike respond appropriately? ***Yes. He observed there was a problem, asked for both sides of the story, and advocated for AJ's rights.***
- How would you support Daniel? ***Approach Daniel privately and make sure that he understands his rights and the rights of others living in the home.***

Show Slide #25: DSP TV video, Scene 6: Confidentiality

- Read and discuss questions at end of Scene 6.

Answers:

- What is the rights issue? ***Individuals have a right to privacy. DSP's should never share personal information about individuals with their friends.***
- Why is this right important? ***Rochelle is working in Bill's home. Of all places, home should be a place that feels safe and comfortable. It may not feel that way if Bill feels he cannot trust the people close to him to maintain confidentiality about his personal life.***
- How would you advocate for Bill? ***Initiate a private conversation with Rochelle and remind her of Bill's rights. Talk to the administrator or service coordinator if necessary.***



Prevention and Problem-Solving Rights “Issues”

The DSP must always be on the alert for possible “issues,” or violations of individual rights. Issues may occur between:

- Individuals where one person’s rights infringe on another’s
- Individuals and staff
- Individuals and conservators
- Individuals and family members

All issues are not necessarily rights issues, but they may be thought of as violations by the individual. The DSP must:



- Carefully evaluate each situation, talk to the individuals involved, think about what you have observed.
- Talk to other staff to find out what they have seen and heard.
- Talk to your administrator. You may also want to talk to the service coordinator for the individual.

There are actions that the DSP can and must take to prevent rights violations:

- When an individual moves to a home, he or she must be given understandable information about his or her rights.
- A copy of the Lanterman Act rights must be posted in an area where everyone can see it.
- Individuals must also be informed of both internal and external grievance and complaint procedures and be provided with names and phone numbers of advocacy agencies and the Consumer Rights Advocate.

CCL requires agreed-upon house rules that reflect the concerns and preferences of the individual living in the home. The purpose of house rules is to create an environment where people can live together in harmony and not infringe on each other’s rights. Everyone—staff and individuals living in the home—should know what the house rules are and have a written copy.

It is a good idea to have regular meetings that include both staff and individuals living in the home, during which individuals discuss and resolve issues, make decisions regarding household issues (for example, recreational activities, group outings, menus, and changes in house rules), and discuss rights.

DSPs must be knowledgeable of individual rights, house rules, and both internal and external consumer grievance and complaint procedures and be prepared to support individuals in following these procedures. Regional centers have videos, posters, and other materials that may be helpful. Ultimately, you will have to decide if you believe a rights violation has occurred because they are “reportable incidents,” which will be discussed in the next session.



Trainer Guide: SESSION 2

Prevention and Problem Solving Rights “Issues” (cont.)

Show Slide #26: DSP TV video, Scene 7: Mail and Phone Conversations

- Click on the icon to show the video.
- Read and discuss questions at end of Scene 7.

Answers:

- What is the rights issue? ***Individuals have the right to communicate with whomever they please, whenever they please. To prevent them from doing so is a violation of that individual’s right to be free from harm and a form of abuse called isolation.***
- Why is this right important? ***Having relationships greatly improves people’s quality of life.***
- How would you advocate for Daniel? ***Initiate a private conversation with Kami and remind her of Daniel’s rights and/or her own liability if she should violate this right. Talk to the administrator or service coordinator if necessary.***



Show Slide #27: DSP TV video, Scene 8: Making Choices

- Click on the icon to show the video.
- Read and discuss questions at end of Scene 7.

Answers:

- What is the rights issue? ***Individuals have the right to personal time, space and possessions, and to recreation. This means that Daniel has a right to listen to whatever music he enjoys and to have his own radio.***
- Why are these rights important? ***Choosing how to enjoy one’s free time and having possessions to call your own greatly improves people’s quality of life.***
- How would you advocate for Daniel? ***Initiate a private conversation with Kami and remind her of Daniel’s rights. Talk to the administrator or service coordinator if necessary.***



Locating and Using Advocacy

Show Slide #28: Locating and Using Advocacy

- Review information in the Student Guide.
- Refer students to Appendix 2-B for more information on each agency.
- Review what advocacy is and is not in the gray box in the Student Guide.



Locating and Using Advocacy

A key role of the DSP is to assist individuals and their families to locate and use advocacy services to ensure that their service needs are being met, that services are of good quality and that rights are being respected. The Lanterman Act provides for advocacy services for persons with intellectual/developmental disabilities through the following agencies:

- State Council on Developmental Disabilities and Developmental Disabilities Area Boards: In California, Area Boards provide individual advocacy. A DSP may contact them to obtain information on behalf of an individual or information to assist the individual to advocate for him or herself.

- Disability Rights California (DRC): DRC is responsible for protecting the rights of individuals. Services include legal counseling and representation for individuals. DRC has Consumer Rights Advocates specially assigned to provide individual advocacy services.

In California, another resource for self-advocacy is People First of California, Inc. People First has chapters throughout California and publishes a newsletter with information about self-advocacy, *People First Star*. People First chapters help individuals learn about their rights and how to speak up for themselves.

Advocacy is:

- Helping individuals help themselves
- Building self-confidence
- Supporting independence
- Telling individuals their rights
- Telling individuals their options
- Providing assistance and training
- Helping locate services
- Asking individuals what they want
- Treating adults like adults

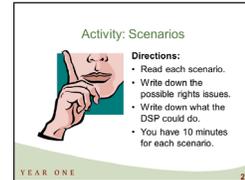
Advocacy is not:

- Taking over an individual's life
- Making an individual dependent
- Doing everything for an individual
- Withholding information about an individual's rights
- Making decisions for individuals
- Controlling individuals
- Making adults feel like children
- Limiting options
- Knowing what is best because you are a professional
- Ignoring choices

Trainer Guide: SESSION 2

Show Slide #29: Activity: Scenarios

- Groupings: individual or small group.
- Directions: Read each scenario. Instruct students to identify possible rights issues and what the DSP could do to advocate for the individual and/or support the individual to advocate for him or herself in each scenario. Students may note answers in the spaces provided.
- Give students approximately 10 minutes to complete each scenario.
- Walk around the room and assist students that need help.
- Facilitate a discussion after each scenario.



Scenario #1: Charles

Answers:

- Possible rights issues:
 - He borrows tape recorders and clothing from other individuals living in the home. He violates their rights to have and use personal possessions.
 - He hates getting up in the morning. The DSP makes him get up on weekends as punishment. This is a violation of Charles' right to choose when to get up in the morning.
 - The DSP takes Charles' radio away as punishment for bad behavior. This is a violation of his right to have and use personal possessions.
 - Charles is only allowed to leave the facility once a month. This is a violation of his right to social interaction and participation in community activities.
 - Charles is "made" to participate in activities with other residents. This violates his right to choose how he spends his time.
 - The DSP often makes Charles leave the kitchen when meals are being prepared. This is also a violation of his right to choose how he spends his time.
- The DSP could:
 - Talk to Charles to ensure that he understands his rights and the rights of other individuals living in the home.
 - Talk to Charles' Service Coordinator to determine if any of the possible rights violations must be reported.
 - Talk to Charles' Service Coordinator to determine if the person-centered planning team should meet to discuss his challenging behavior and develop alternate strategies to help him meet his needs.
 - Offer choices to Charles about how he would like to spend his free time. Include some options which are in the community and some that include meeting other people than the individuals he lives with.

A C T I V I T Y

Directions: After reading the scenario, list the possible rights issues. You can refer back to the sections on individual rights. Then write down what the DSP can do to advocate for the individual or support the individual in advocating for him or herself.

SCENARIO #1: CHARLES

Charles is 42 years old and has cerebral palsy and epilepsy. It can be difficult for some people to understand him when he talks. He hasn't seen his family in a long time, and it is unknown if he even has family still living. He sometimes wanders away from the home and tends to "borrow" tape recorders and clothing from other individuals living in the home. Charles doesn't eat much, plays with food on his plate, and occasionally throws food. He doesn't like getting up in the morning and has to be repeatedly asked to get out of bed. The DSP in the home makes Charles get up early on weekends because he won't get up on weekdays. He loves to sit outside on weekends and listen to his radio. It is repeatedly taken away for bad behavior and not getting up in the mornings.

When other residents have family or visitors, Charles gets very excited and wants to go with them if they leave the home. He often sneaks out of the home right after visitors leave and gets very angry when he is brought back. He is only allowed to leave the facility once a month when the group goes on an outing. He doesn't initiate activities often and only participates with other residents when made to do so. He tends to hang out in the kitchen when meals are being prepared. The DSP thinks Charles gets in the way in the kitchen and often makes him leave the room until the meal is ready.

Possible rights issues:

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What could the DSP do to advocate for the individual and/or support the individual in advocating for him or herself?

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Trainer Guide: SESSION 2

Scenario #2: Michael

Answers:

- Possible rights issues:
 - Michael is locked in his room and left there as a punishment. This is a violation of his rights to treatment and habilitation services and supports. It is also a violation of his rights to dignity, privacy and humane care.
 - DSPs forget grooming tasks when Michael is particularly uncooperative. This is a violation of his right to humane care.
 - Michael does not want to go to his family’s house, but is apparently made to do so. This is a violation of his right to choose how he spends his time.
 - Someone needs to determine if Michael gives away his personal possessions or if they are being taken. He has a right to keep and use his personal possessions.
 - Michael loses telephone privileges until he promises not to talk so long. The right to use the telephone may not be taken away for long periods of time unless the denial of rights for good cause has been done, and then only for 30 days. During that time, a plan must be developed to help him realize how long he is on the telephone.

- The DSP could:
 - Talk to Michael’s Service Coordinator to determine if any of the possible rights violations must be reported.
 - Talk to Michael’s Service Coordinator to determine if the person-centered planning team should meet to discuss his challenging behavior and develop alternate strategies to help him meet his needs.
 - Offer Michael choices about what he would like to do outside the home and with his friends. Discuss the importance of “looking good” for his friends and help him understand how his appearance and grooming affect his relationship with others.

A C T I V I T Y

SCENARIO #2: MICHAEL

Michael is 18 years old. He uses a wheelchair and requires assistance for his daily care. He often yells very loudly and is locked in his room and left there as punishment. He uses his manual wheelchair independently, but he needs assistance to transfer himself from his wheelchair. He is usually uncooperative with DSPs in daily grooming and bathing. DSPs sometimes comb his hair but do not do the other grooming tasks when he is especially uncooperative.

Michael's family visits him in his home regularly and takes him to their home on a monthly basis. He says he doesn't want to go, and he is unhappy and grumpy for several days afterward. Michael gets along well with one of the other young men living in the home and often spends hours in his company. He likes to share his personal possessions and often gives them away. He likes to talk on the telephone and spends hours talking to friends. His telephone privileges are often taken away for long periods of time until he promises not to talk so long.

Possible rights issues:

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What could the DSP do to advocate for the individual and/or support the individual in advocating for him or herself?

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Trainer Guide: SESSION 2

Scenario #3: Mary

Answers:

- Possible rights issues:
 - Mary violates the rights of others to humane treatment when she threatens them, and screams and cries for several hours at night.
 - Mary is kept in her room as punishment for her behavior. This is a violation of her rights to social interaction and participation in community activities.
 - Mary's rights to treatment, and habilitation services and supports, dignity, religious freedom and practice, social interaction and participation in community activities are all violated when she is not allowed to do any special things because of her behaviors.

- The DSP could:
 - Talk to Mary to ensure that she understands her rights and the rights of other individuals living in the home.
 - Talk to Mary's Service Coordinator to determine if any of the possible rights violations must be reported.
 - Talk to Mary's Service Coordinator to determine if the person-centered planning team should meet to discuss her behavior and develop alternate strategies to help her meet her needs.
 - Offer Mary choices about what she would like to do outside the home and with her friends.

A C T I V I T Y

SCENARIO #3: MARY

Mary is 34 years old. She has depression and sometimes yells, screams, curses, or hurts herself. She also threatens peers at home and in the community. Mary is often kept in her room as punishment for her behavior. She is not allowed to go on outings with the group if she has been threatening peers. It is easier to leave her at home. Mary cries and screams for several hours at night, which keeps staff and other individuals awake. The DSPs ignore her and let her cry and scream until she wears herself out and finally goes to sleep.

Mary says she is not a baby and feels bad when she is treated like one. She says she wants to feel loved and not be so lonely. She wants to help children with disabilities. She wants to go to church, sing in the church choir, learn how to take care of herself, cook, and do her own laundry. The DSP will not let Mary do any special things because of her behavior. The DSP tells her that when she changes her behavior, he will help her learn to do some of the things she wants to do.

Possible rights issues:

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What could the DSP do to advocate for the individual and/or support the individual in advocating for him or herself?

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Trainer Guide: SESSION 2

Scenario #4: Charlene

Answers:

- Possible rights issues:
 - Charlene's rights to privacy and to have individual storage space for private use are violated when the DSP removes her collection from her dresser drawers and throws it into the trash.
 - Charlene's right to keep and spend a reasonable amount of her own money is violated when the DSP keeps her money and makes her wait until he or she can go to the store with Charlene.
 - Charlene's rights to have visitors, make choices about her companions, leisure and social activities, and have relationships are violated when the administrator tells her that she is not allowed to have male visitors at home and she cannot go on dates.
- The DSP could:
 - Talk to Charlene's Service Coordinator to determine if any of the possible rights violations must be reported.
 - Talk to Mary's Service Coordinator to determine if the person-centered planning team should meet to discuss her desire to have her boyfriend over and to date. Team could develop strategies and circumstances that would allow that to happen.
 - Offer Mary choices about what she would like to do with her collections. Find ways to help her organize her treasures and discuss the possibility of getting rid of some of the less important things.

Show Slide #30: 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

SCENARIO #4: CHARLENE

Charlene is 35 years old. She is very verbal, healthy, and active at home, at work, and in the community. She loves to shop for clothing and go to movies, dancing and parties, and to help with chores at home. She also likes to collect brochures, newspapers, magazines, and small pieces of paper, which she puts in her dresser drawers. DSPs go into her room periodically and remove her collection, throwing it in the trash because there isn't enough room in her drawers for her clothes anymore.

Charlene knows all the merchants in her neighborhood. She tends to purchase lots of "junk" items so the DSP keeps her money and makes Charlene wait until she can go with her to the store. Charlene has a male friend, Sam, and wants to have him visit her once in awhile. The administrator of the home has told Charlene that she is not allowed to have male visitors. She has also been told that she cannot go out on a date with Sam or any other male friend.

Possible rights issues:

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What could the DSP do to advocate for the individual and/or support the individual in advocating for him or herself?

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

Look for a copy of the Lanterman Act Rights in the home where you work. Where is it posted? Ask an individual you support if he or she knows about his or her rights. What rights does the individual know about? Do you think that the individual needs more information? If so, do you have some ideas about how to help the individual learn more about their rights? Be ready to share at the beginning of the next session.

Trainer Guide: SESSION 2

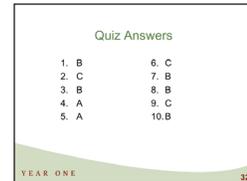
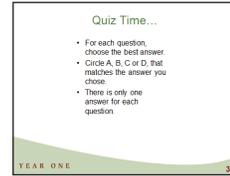
Quiz: The California Developmental Disabilities Service System

Show Slide #31: Quiz Time

- Give the students 20 minutes to take the quiz.

Show Slide #32: 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. B
2. C
3. B
4. A
5. A
6. C
7. B
8. B
9. C
10. B

End of Session 2

The California Developmental Disabilities Service System

1. **The organizations known as Disability Rights California, the State Council on Developmental Disabilities, and the Department of Developmental Services:**
 - A) Make up the leadership and staff of each regional center
 - B) Work with the regional centers to ensure quality services to support individuals with intellectual/developmental disabilities under the Lanterman Act
 - C) Send representatives to participate on each individual's person-centered planning team during the development of the IPP
 - D) Fund generic services for individuals with developmental disabilities
2. **The Department of Developmental Services (DDS) writes and revises Title 17 regulations, which are rules guiding the work of:**
 - A) Hospitals and clinics
 - B) Local education agencies
 - C) Regional centers and vendors
 - D) Homes and work places
3. **Regional centers provide a variety of services to individuals, including:**
 - A) Routine medical treatment
 - B) Coordination of services identified in an Individual Program Plan (IPP)
 - C) Basic household utilities
 - D) Local transportation services through a Special Vehicle Network (SVN)
4. **An IPP is a written agreement between the individual and the Regional Center that:**
 - A) List the individual's goals and the services and supports needed to reach those goals
 - B) Is developed through a process of person to vendor planning
 - C) Is developed by the planning team and the vendor
 - D) Is developed without the individual at the IPP meeting
5. **Developmental Disabilities Area Boards are located throughout California to carry out the mission of the:**
 - A) State Council on Developmental Disabilities
 - B) Department of Developmental Services
 - C) Local regional centers
 - D) Department of Social Services
6. **The Department of Social Services writes and revises Title 22 regulations which are rules for:**
 - A) Recreation programs
 - B) Regional centers
 - C) Community care licensed homes
 - D) Education programs

Session 2 Quiz (cont.)

7. 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

8. **A vendor is an individual or agency who:**

- A) Has a special product to sell
- B) Has a contract with a regional center to provide specific services and supports
- C) Has a copy of the Lanterman Act and the Title 17 regulations
- D) Has made a commitment to volunteer their time to support an individual in some way

9. **The Lanterman Act says that individuals with developmental disabilities have:**

- A) No rights because they need too much support
- B) Certain rights, if they behave appropriately
- C) The same rights as everyone else
- D) Special rights that no one else has

10. **California People First helps individuals learn about:**

- A) Services and supports that are vendored by the regional center
- B) Self-advocacy, their rights, and how to speak up for themselves
- C) Legal counseling and representation
- D) Person-centered planning and service coordination

Appendices



Appendix 2-A

Laws and Regulations

- **Rehabilitation Act of 1973:** This Act is known as the first federal civil rights law protecting the rights of individuals with disabilities. It prohibits discrimination based on disability in the following areas: (1) education; (2) vocational education; (3) college programs; (4) employment; (5) health, social service programs, welfare; and (6) federally funded programs.
- **The Americans with Disabilities Act (ADA):** Congress passed this law in July of 1990. It is landmark civil rights bill that protects against discrimination of people with disabilities. It requires modifications, accessibility, and reasonable accommodations; covers state and local governments; and addresses four main areas of potential discrimination: (1) employment; (2) public facilities; (3) transportation; (4) communication.
- **Individuals with Disabilities Education Act (IDEA):** Guarantees six important rights; (1) free and appropriate public education (FAPE) for all children with disabilities; (2) education in the least restrictive environment; (3) an individual education program (IEP); (4) provision of necessary related services in order to benefit from special education; (5) fair assessment procedures; and (6) due process and complaint procedures.
- **IDEA, Part C:** Early intervention and education services available to infants and toddlers less than 3 years of age who have or are at risk for a developmental delay or disability.
- **Title 17:** Copies of Title 17 may be obtained at a local regional center; by contacting Barclays Law Publishers, PO Box 2006, San Francisco, CA 94126 (800) 888-3600; or at the Dept. of Developmental Services website, <http://www.dds.ca.gov/Title17/Home.cfm>
- **Title 22:** Copies of Title 22 may be obtained at a local licensing office or by contacting Barclays Law Publishers, PO Box 2006, San Francisco, CA 94126 (800) 888-3600 or at the Dept. of Social Services website, <http://cclld.ca.gov/PG555.htm>
- **The Lanterman Act:** A copy of the Lanterman Act may be obtained at the Dept. of Developmental Services website, <http://www.dds.ca.gov/Statutes/LantermanAct.cfm>

Agencies Supporting Individuals with Developmental Disabilities

A number of agencies and organizations support individuals with developmental disabilities, such as:

- **Health and Human Services Agency:** The umbrella agency for the Departments of Social Services, Health Care Services, Developmental Services, Mental Health, and Rehabilitation.
- **Department of Social Services (DSS):** Licenses homes for children and adults with intellectual/developmental disabilities through its Community Care Licensing Division.
- **Department of Health Care Services (DHCS):** Administers the Medi-Cal program that pays for health care. Also licenses and monitors homes for people with developmental disabilities and significant health needs.
- **Department of Developmental Services (DDS):** Contracts with 21 regional centers to provide services to children and adults with developmental disabilities. DDS is also responsible for managing the state developmental centers.
- **Department of Mental Health (DMH):** Oversees county mental health services.
- **Department of Rehabilitation (DR):** Provides funding for Work Activity Programs (WAPs), which include work support services in sheltered and community-based employment settings.
- **Department of Education (DOE):** Manages education programs in the public school system, including special education services.
- **Special Education Local Plan Area (SELPA):** Local educational service areas throughout the State of California that manage regional educational programs for students with disabilities ages birth through 21 years of age.
- **Local School Districts:** Provide educational services to children with disabilities ages birth through 21 years of age.
- **State Council on Developmental Disabilities (SCDD):** Develops a state plan, which looks at the future of services for individuals with developmental disabilities; reviews and comments on budgets and state agency regulations that provide services to people with developmental disabilities; and funds area boards.
- **Disability Rights California (DRC):** Protects the civil and service rights of Californians with developmental disabilities through legal advocacy.
- **Developmental Disabilities Area Boards:** Protect the rights of Californians with developmental disabilities through public information and education and by monitoring policies and practices of agencies that are publicly funded.