



# Student Resource Guide

## 2. The California Developmental Disabilities Service System





# 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 intellectual/developmental disabilities as described in the Lanterman Act.
- Describe the new residential facilities and their purpose.

## KEY WORDS

| Key Word  | Meaning  | In My Own Words |
|---|--|-----------------|
| <b>Community Care Facilities</b>                | Homes operated by people or agencies who are granted a license by the State of California to provide residential care.   |                 |
| <b>Community Crisis Homes (CCH)</b>             | Community Crisis Homes (CCH) are adult residential facilities that provide 24-hour non-medical care to individuals with intellectual/developmental disabilities (I/DD) receiving regional center services, are in need of crisis intervention services, and who would otherwise be at risk of admission to a more restrictive setting. |                 |
| <b>Confidentiality</b>                          | Keeping information about an individual private; sharing information about an individual only with permission to do so.  |                 |
| <b>Denial of Rights</b>                         | 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.   |                 |
| <b>Enhanced Behavioral Support Homes (EBSH)</b> | Enhanced Behavior Supports Homes (EBSH) are adult residential facilities or group homes that provide 24-hour non-medical care to individuals with I/DD who require enhanced behavioral supports in a homelike setting.   |                 |

**KEY WORDS (CONT.)**

| Key Word                                 | Meaning  | In My Own Words |
|--|--|-----------------|
| <b>Goal</b>                              | Things described in an Individual Program Plan that the individual wants in his or her future; goals reflect the individual's needs and preferences.   |                 |
| <b>Individual Program Plan (IPP)</b>     | 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.  |                 |
| <b>Individual's Rights</b>               | 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.   |                 |
| <b>Legally Authorized Representative</b> | Parent(s) or legally appointed guardian of a minor child, or legally appointed conservator of an adult.  |                 |
| <b>Person-Centered</b>                   | Based on the needs, preferences, and choices of the individual with the developmental disability.  |                 |
| <b>Planning Team</b>                     | 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. |                 |
| <b>Preferences</b>                       | Choices that the individual makes.   |                 |
| <b>Regional Center</b>                   | One of 21 centers created by the Lanterman Act and located throughout California. Regional centers assist individuals with intellectual/developmental disabilities and their families to find and access services.   |                 |

## KEY WORDS (CONT.)

| Key Word                     | Meaning  | In My Own Words |
|------------------------------|--|-----------------|
| <b>Service Coordinator</b>   | A regional center representative who works with individuals and families to find and organize access to needed services and supports.                      |                 |
| <b>Services and Supports</b> | Assistance provided for the individual to lead the most independent and productive life possible, based on the individual's needs, goals, and preferences. |                 |
| <b>Title 17</b>              | Regulations for regional centers and regional center vendors including vendored community care facilities.   |                 |
| <b>Title 22</b>              | Regulations for licensed community care facilities.  |                 |

**A C T I V I T Y**

**What Do You Want to Know?**

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

.....  
What do you **already know** about the 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?

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 intellectual/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)
- 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.

## 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 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.

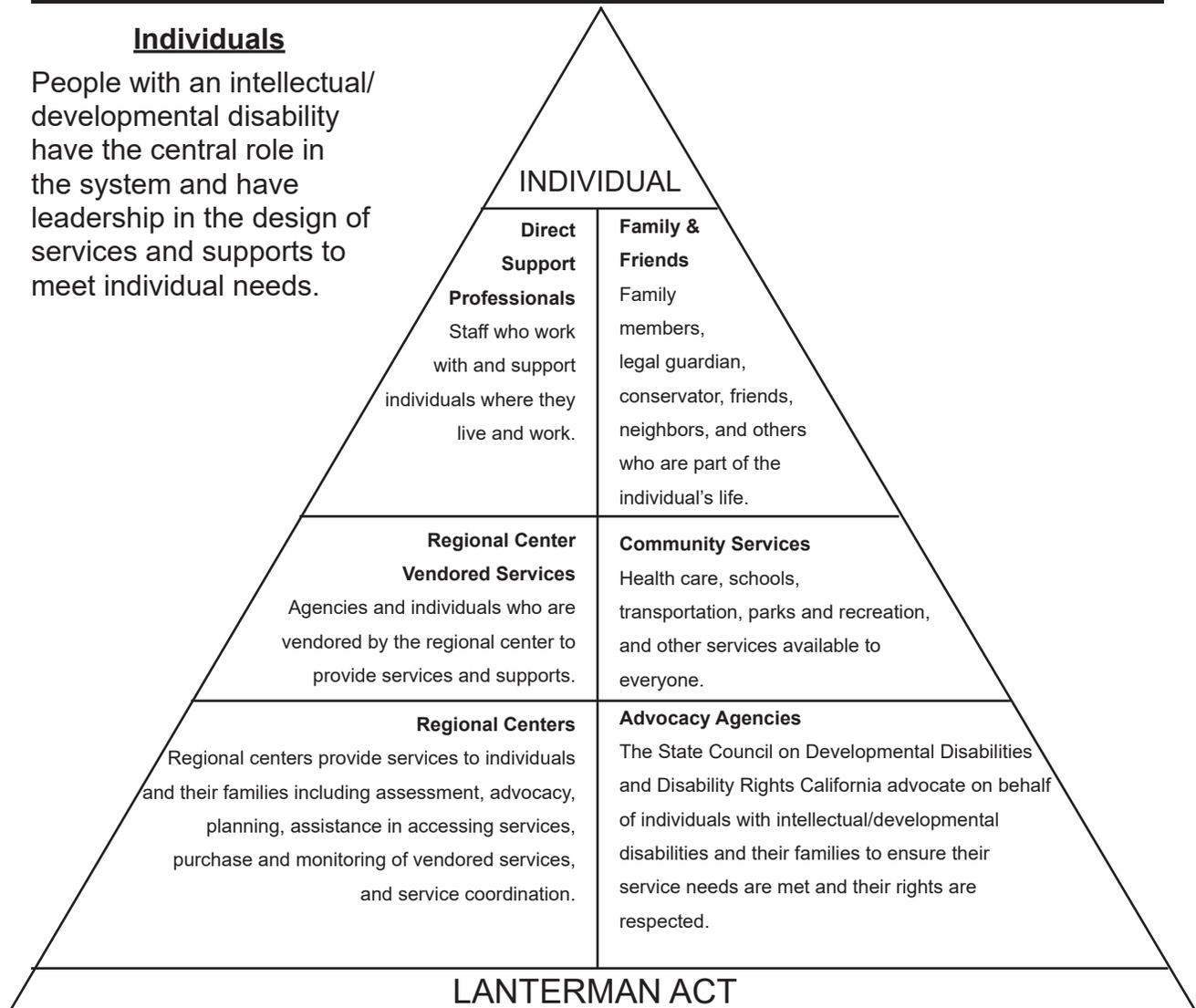
There is a whole network of people and agencies that are working to support individuals and their families in addition to DSPs. These agencies and individuals make up the developmental disabilities service system in California, and all have a common goal of ensuring quality services to support individuals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



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.

### New Residential Facilities

The Department of Developmental Services recognizes that individuals with intellectual/developmental disabilities (I/DD) are requiring more intensive services and supports to help them live successfully in their communities. To help with this, there are new residential options in development. These new options will lower the risk of admission to a more restrictive setting. These new alternative living options will also be available to individuals moving out of developmental centers (DC). A majority of the individuals still living in the DCs will need more intensive services and supports as they transition into the community. Regional centers across the state have been working to provide alternative living options for the remainder of these harder to place individuals, as well as those currently living in the community.

#### Community Crisis Homes

Community Crisis Homes (CCH) are adult residential facilities that are certified by the Department of Developmental Services (DDS) and licensed by the Department of Social Services (DSS). They provide 24-hour non-medical care to individuals with I/DD receiving regional center services, are in need of crisis intervention services, and who would otherwise be at risk of admission to a more restrictive setting. In addition, these homes provide additional assessment, staffing, supervision, and other intensive services and supports to address the individual's urgent/immediate behavioral needs, which are not provided in other community living arrangements. Since these are crisis homes, there is a preferred 18-month time limit on how long an individual can remain.

#### Enhanced Behavior Support Homes

Enhanced Behavior Support Homes (EBSH) are certified by DDS and licensed by DSS as residential facilities or group homes that provide 24-hour non-medical care to individuals with I/DD who require enhanced behavioral supports in a homelike setting. The enhanced behavioral services and supports are provided to address individuals' challenging behaviors including additional staffing, supervision, facility characteristics, and other services and supports which are beyond what is typically available in other community-based adult residential facilities or group homes to serve individuals in a community setting rather than an institution.

## 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.

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. The

### A C T I V I T Y

#### 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?

# Individual Rights

Lanterman Act says that individuals with intellectual/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.

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**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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### **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.

## 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.

## 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

## 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)

## 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.



## 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 (also known as Developmental Disabilities Area Boards). In California, this agency provides 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 has a variety of publications relating to self-advocacy. People First chapters help individuals learn about their rights and how to speak up for themselves.

| <b><i>Advocacy is:</i></b>  | <b><i>Advocacy is not:</i></b>   |
|---|--|
| <ul style="list-style-type: none"> <li>• Helping individuals help themselves</li> <li>• Building self-confidence</li> <li>• Supporting independence</li> <li>• Telling individuals their rights</li> <li>• Telling individuals their options</li> <li>• Providing assistance and training</li> <li>• Helping locate services</li> <li>• Asking individuals what they want</li> <li>• Treating adults like adults</li> </ul> | <ul style="list-style-type: none"> <li>• Taking over an individual's life</li> <li>• Making an individual dependent</li> <li>• Doing everything for an individual</li> <li>• Withholding information about an individual's rights</li> <li>• Making decisions for individuals</li> <li>• Controlling individuals</li> <li>• Making adults feel like children</li> <li>• Limiting options</li> <li>• Knowing what is best because you are a professional</li> <li>• Ignoring choices</li> </ul> |

**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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**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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**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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**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.

### 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://ccl.d.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 intellectual/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 intellectual/developmental disabilities and significant health needs.
- **Department of Developmental Services (DDS):** Contracts with 21 regional centers to provide services to children and adults with intellectual/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 (DOR):** 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 intellectual/developmental disabilities; reviews and comments on budgets and state agency regulations that provide services to people with intellectual/developmental disabilities; and funds area boards.
- **Disability Rights California (DRC):** Protects the civil and service rights of Californians with intellectual/developmental disabilities through legal advocacy.
- **Developmental Disabilities Area Boards (also known as SCDD):** Protect the rights of Californians with intellectual/developmental disabilities through public information and education and by monitoring policies and practices of agencies that are publicly funded.