

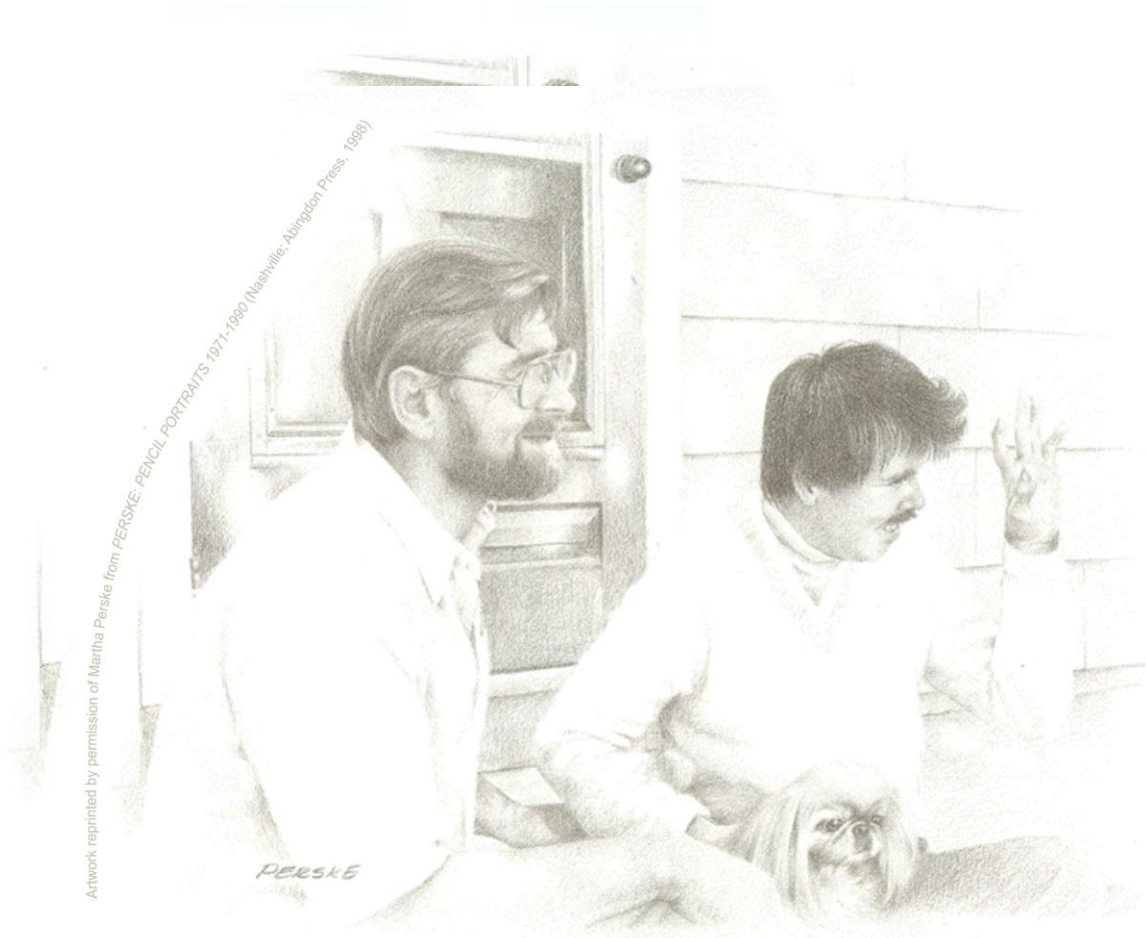
# RIGHTS UNDER THE LANTERMAN ACT

## *Living Arrangements For Adults And Children*

### Chapter 7

This chapter explains options and rights in living arrangements, including:

- Supported and independent living
- Foster family and small group homes
- Small and large institutions



# Chapter 7: Living Arrangements for Adults and Children

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Supplement N: [How to Write A letter to Ask for an IPP](#)  
Supplement O: [How to Choose a Supported Living Agency](#)

# Choosing A Living Arrangement

*This chapter gives you answers to the most common questions about the living arrangements available to adults and children with developmental disabilities.*

*There are many options, including:*

- *living at home, at a relative's home, or foster family's home,*
- *living in a group home with other people with developmental disabilities,*
- *living in an institution, like a developmental center, or nursing home, or other facility.*

*We explain what each option is like, and how to plan or develop the living arrangement that is best for you. You will also learn about the rights you have in the living arrangement you choose.*

*This information is based on a state law called the Lanterman Act. You may have to refer to this law to get the services you need. The § symbol means section. So when you see § 4512(a), for example, it means this information comes from the Lanterman Act, section 4512, part a.*

*If you want to read the Lanterman Act, go to:*

*<http://www.dds.ca.gov/Statutes/LantermanAct.cfm>*

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## **1. What choices do I have about where I will live?**

Adults and children with disabilities live in many different kinds of living arrangements. They include living:

- with your parent or a relative or friend at their home (See *Chapter 6.*),
- in your own home or apartment, with the supports you need,
- with a foster family,
- in a small group home in a regular neighborhood, or
- in an institution, like a developmental center, nursing home, or other facility.

Deciding where you want to live is part of the planning process for your IPP. Your preferences, choices, and wishes are the starting point for deciding where you will live.

There is a range of different kinds of living arrangements. The range is sometimes called a “continuum” starting with the least restrictive and most integrated (such as independent or supported living) up to the most restrictive and least integrated (such as a locked unit at a developmental center). You do not have to move through this “continuum” or be ready for a more integrated or less restrictive living arrangement.

Services and supports for people with developmental disabilities have changed over the last 30 years. And, more and more people are living in their own homes or small group homes in regular neighborhoods and natural communities, instead of in developmental centers or other large congregate institutions.

The law says services must be provided in the least restrictive settings. The Lanterman Act has a strong emphasis on the need to provide integrated community living arrangements.<sup>1</sup> For more information about your right to stay out of or move out of an institution see Chapter 9.

## **2. What options are available if I do not live at my home or with a relative?**

If you do not live at home or at a relative’s home, you may live in a community *home* or in an *institution*.

Here are other kinds of **homes** where you could live:

### **For adults:**

Independent Living. (See *Question 4*.)

Supported Living Arrangement. (See *Question 6–15*.)

Family Home Agency Foster Homes. (See *Question 18*.)

Family Teaching Homes. (See *Question 19*.)

### **For children:**

Bates Homes. (See *Question 16*.)

Foster Family Agency (FFA) Foster Homes. (See *Question 17*.)

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<sup>1</sup> §§ 4501, 4502(a) and (b), 4689.

**For adults or children:**

Small Residential Care Facilities (ARM Level CCF or ICF-DD-H or ICF-DD-N or ICF-DD-CN). *(See Questions 20–23.)*

Here are options where you would live in an **institution**:

Large Community Care Facility (CCF). *(See Question 20.)*

Large Intermediate Care Facility (ICF-DD). *(See Questions 28.)*

Nursing Facility (NF). *(See Question 31.)*

Sub-acute Facility. *(See Question 33.)*

Developmental Center. *(See Question 30.)*

Psychiatric Facility. *(See Question 32.)*

Wherever you live, you have rights and responsibilities. To learn more about your rights and responsibilities, read Questions 39-43.

**3. Can I live independently even if I need support?**

Yes! The law says that people with developmental disabilities must get the support they need so they can enjoy the same kinds of living arrangements as people without disabilities.<sup>2</sup> This means you can live in your own home and receive the support you need. It does not matter if you need a little support or a lot of support.

*Everybody* needs some help to live “independently.” We all depend on others, like family, friends, neighbors, gardeners, plumbers, and baby sitters for some kind of support. Similarly, you may receive the support you need to live independently from family, friends, neighbors, and paid caregivers.

Regional centers call these services “supported living” or “independent living skills” services. *(See Questions 5 and 6 for more information.)*

**4. What are “independent living skills”?**

Independent living skills (called ILS for short) are the skills you need to learn to live independently in your community. There are ILS programs that can teach skills, such as:

cooking,

housecleaning,

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<sup>2</sup> §§ 4501, 4502(a) and (b), 4689.

grooming, and  
money management.<sup>3</sup>

You can receive ILS services in your parents' home, a licensed facility, or your own apartment. You have the right to receive ILS services until you learn the skills you need to live on your own.

Some regional centers say you can only get these services for a certain amount of time. But the law says you have the right to get ILS services for as long as you need them and can show that you benefit from them.<sup>4</sup> (You may need to have an individual assessment to prove your need and the benefit.)

Some people may already have basic self-help skills but still need ILS in certain areas to remain independent. For example, you may need help with:

Paying your bills, and

Planning your meals.

In most cases, people with basic self-help skills who need a little extra help can get up to 15 hours of support per week.

You can also use ILS services to hire and supervise someone to help you with self-care or other activities that you cannot do yourself and are not provided by other agencies.<sup>5</sup>

## 5. What are “supported living services”?

Supported living services (called SLS for short) are services that support people with developmental disabilities so they can live in their

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<sup>3</sup> Cal. Code Regs., tit. 17 § 54302(a)(35).

<sup>4</sup> In *Williams v. Macomber*, 226 Cal.App.3d 225 (1990), the state appellate court found that “the Regional Center’s reliance on a fixed policy is inconsistent with the Act’s stated purpose of providing services ‘sufficiently complete to meet the needs of each person with developmental disabilities’ (§ 4501).” 226 Cal.App.3d at 232. Therefore, regional center policies that place strict time limits on ILS services ignoring your individual needs are contrary to the Lanterman Act. If your regional center tries to put a time limit on your ILS, you may want to appeal. (See *Chapter 12 for more information on the appeal process.*)

<sup>5</sup> IHSS can assist you to pay for personal attendants to help you perform self-care activities such as shopping and cleaning. See Disability Rights California’s publication on IHSS titled “IHSS Fair Hearing and Self-Assessment Packet” available on our website at [www.disabilityrightsca.org/PUBS/501301.htm](http://www.disabilityrightsca.org/PUBS/501301.htm).

own home or apartment. (SLS is not for people who live with their parents or conservators.)<sup>6</sup> In fact, there are about 4,000 adults with developmental disabilities who live in their own homes with SLS.<sup>7</sup>

The guiding principle of SLS is that no matter your degree or type of disability,<sup>8</sup> you should get the support you need as often as you need it, and for as long as you need it so that you can:

Live in a house or apartment that you own or rent,

Make choices and build relationships in the community, and

Live like people without disabilities, as much as possible.

The types of services depend on your needs and preferences. Each SLS plan is different. SLS can be any services that *you* need to live on your own.

For example, you can use SLS to help you:

Develop a “circle of support.”<sup>9</sup> (See *Chapter 4, Question 11.*)

Get training and support in social, behavioral, and daily living skills.

Choose, hire, and train people to help you with personal care, learn new skills, and be involved in leisure, recreational, spiritual, or other activities in your local community. (Some people choose a paid roommate, neighbor, or IHSS worker.)

Manage, direct and, if needed, fire a personal attendant.

Get medical care and other supports you needed to be integrated in your community.

Develop employment goals.<sup>10</sup> (See *Chapter 8, Question 55.*)

You can also change the kinds of SLS you receive as your needs change.<sup>11</sup>

The Legislature recognizes that people with developmental disabilities have the right to have relationships, get married, be part of a family, and

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<sup>6</sup> § 4689(a)(4); Cal. Code Regs., tit. 17 § 58613. But see Chapter 6, Question 42 about getting services like SLS when living in your parent’s home.

<sup>7</sup> Figures are from of July 2005.

<sup>8</sup> § 4689(a)(8).

<sup>9</sup> Cal. Code Regs., tit. 17, § 58601(a)(1).

<sup>10</sup> § 4689(c) provides a non-exhaustive list of the range of supported living services and supports.

<sup>11</sup> § 4689.

have children if they so choose.<sup>12</sup> This means that SLS is also specifically available for parents with developmental disabilities and their children.<sup>13</sup>

## 6. What is the difference between ILS and SLS?

**ILS** (*independent* living skills) is mostly training so you can learn and improve the skills that you need to live on your own. You may also be able to get ILS to remain independent once you are living on your own. You can receive ILS in any setting, even if you live at home with your family or in a licensed facility while you prepare to move out.

**SLS** (*supported* living services) usually includes more direct services. SLS is for people who need more than training to be independent. You can only receive SLS if you live on your own in a home or apartment that you own or rent.

**Note:** Some regional centers do not distinguish between ILS and SLS and may provide similar services under each category. See your regional center's purchase of service (POS) policy for clarification.

## 7. Who is eligible for supported living services?

To receive SLS (*supported* living services) you must:

Be at least 18 years old.<sup>14</sup>

Live in a house or apartment that you own or rent.

If you will be 18 soon, you can ask for an SLS assessment at an IPP meeting to get the process started so you can move when you reach 18.<sup>15</sup>

**Important!** Everyone has the right to get SLS. It is against the law to deny SLS to someone because they are "too disabled."<sup>16</sup>

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<sup>12</sup> § 4687.

<sup>13</sup> § 4687(c).

<sup>14</sup> Cal. Code Regs., tit. 17, § 58613(a)(1).

<sup>15</sup> § 4689(c).

<sup>16</sup> § 4689(a)(8); Cal. Code Regs., tit.17, § 58613(b).

## 8. Who provides and monitors supported living services?

The regional center will contract with a “vendor” to coordinate the services and supports that you need to live in your own home. (These are the services and supports listed in your IPP and supported living plan, which should include SLS services from generic agencies and/or natural supports.) The vendor does not need a special license to provide SLS services.

The vendor may be:

- a supported living agency, or
- a family member or friend, or <sup>17</sup>
- you may coordinate the services yourself.

The regional center will monitor the quality and effectiveness of all of the SLS services you receive, and evaluate your SLS vendor — even if they are your family or friends or someone from a generic agency.<sup>18</sup>

## 9. How do I decide what supported living services I need?

You and your IPP planning team will talk about what you choose and need to help you live independently in your home. Generally an SLS Agency will do a supported living assessment to help you figure out what you want and need.

There are also many organizations and people who can help you plan your SLS services, including:

Your regional center — Most regional centers have SLS coordinators.

Department of Developmental Services (DDS) — **(916) 654-2140**. Ask to speak with someone who knows about supported living services, or order one of DDS’ supported living publications.

Disability Rights California — Ask for publications #5257.01 and #5143.01. (*General Information and Materials on Supported Living Services and Supported Living*)

Connections for Information and Resources on Community Living (CIRCL) — This is a network of people who have many years of experience with supported living. CIRCL helps people think about,

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<sup>17</sup> Cal. Code Regs., tit. 17 § 58616.

<sup>18</sup> § 4689(e); Cal. Code Regs., tit. 17, §§ 58600, *et seq.*

start, and improve supported living services. Contact CIRCL at **(626) 447-5477** or online at: [www.allenshea.com/CIRCL/CIRCL.html](http://www.allenshea.com/CIRCL/CIRCL.html).

California Supported Living Network (CSLN). CSLN is a network of people and providers in California who advocate quality supported living services. Contact CSLN at: [www.supportedliving.com](http://www.supportedliving.com).

Or send a letter to: Connie Saverino – TMI, Inc., 4740 Murphy Canyon Road, #300, San Diego, CA 92123.

## **10. Who pays for supported living services?**

In a supported living arrangement you must use your SSI or other income to pay your rent or mortgage, food, electricity, telephone and other utilities, and entertainment expenses.

The regional center can pay an SLS Agency or other vendor for the supported living services and supports that you and your IPP planning team determined you want and need to be able to live in your own home. However, before the regional center agrees to purchase any particular supported living service, your planning team will discuss whether that service can be provided by your “natural supports” (friends or family) or by a generic agency. An example of a generic agency support is IHSS paying for people who can help you with personal care.<sup>19</sup>

You will have additional expenses when you are first moving into your own home. You (or your family or friends) have to pay the move-in expenses, including security deposits, furniture, etc. You may also be referred to community resources that can pay for or provide furniture.

*Exceptions:* Under certain limited circumstances if you and your family and friends cannot afford your move-in or ongoing expenses and it will save the state money, your regional center can assist by paying for moving fees, rental or utility deposits, furniture or ongoing rental or lease payments or utility costs.<sup>20</sup>

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<sup>19</sup> See Disability Rights California’s manual on IHSS, “IHSS Fair Hearing and Self-Assessment Packet.” It is available at our website at: [www.disabilityrightscalifornia.org/PUBS/501301.htm](http://www.disabilityrightscalifornia.org/PUBS/501301.htm).

<sup>20</sup> The executive director of the regional center must determine that the costs cannot be paid by other means, including available natural or generic supports, and payment of the cost would result in savings to the state with respect to the cost of meeting the consumer’s overall services and supports needs. Cal. Code Regs., tit. 17, § 58611(b).

## **11. Can the regional center deny my supported living services if they believe it costs too much?**<sup>21</sup>

No. The law says that all services and supports that the regional centers buy must be “cost-effective.”<sup>22</sup> But there is no legal limit on the cost of your SLS services. However, there is a DDS regulation that says the cost of your SLS services must not be more than the cost of regional center services for one year if you were living in an appropriate licensed residential facility.<sup>23</sup>

This limit is called a “cost-cap.” And each regional center interprets it differently. Some regional centers have a complicated way to decide if your SLS is above the “cost-cap.”

Disability Rights California believes the cost-cap regulation is illegal for two reasons:

It is inconsistent with the Lanterman Act, and

It ends up denying SLS to some people based on how “disabled” they are.

Several hearing officers have agreed with Disability Rights California and have refused to apply the regulation. In one case, DDS tried to appeal one of these administrative decisions, but was unsuccessful.

For more information and administrative hearing decisions on the cost-cap regulation, please contact Disability Rights California and ask for publication 5396.01, *Supported Living – Administrative Hearing Decisions Overturning the Cost Cap Regulation*.

## **12. How does the regional center decide if my SLS are “cost-effective”?**

Cost-effective is defined as “obtaining the optimum results for the expenditure.”<sup>24</sup> Disability Rights California believes this means that the money used to provide you with the SLS services you need to live independently, is spent wisely. In other words, you “get the best bang for your buck.”

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<sup>21</sup> § 4689(e); Cal. Code Regs., tit. 17, §§ 58600, *et seq.*

<sup>22</sup> See, e.g., §§ 4512(b), 4646(a), 4648(a)(1)(6), 4651(a), and 4685(c)(3).

<sup>23</sup> Cal. Code Regs., tit. 17, § 58617.

<sup>24</sup> Cal. Code Regs., tit. 17, § 58501(a)(6).

The regional center and your IPP team may look at cost in deciding on a provider or a method of reaching a goal. But, cost cannot be the only consideration. Quality and your preferences must also be considered. No one can make you accept the cheapest service if it will not achieve your goals. But, if a less expensive vendor can help you achieve your goal, you may have to use that vendor. Sometimes, this means you cannot get the SLS vendor you most want, or a particular method of reaching a goal.

### **13. How do I get SLS from my regional center?**

Follow these steps:

Ask for an IPP meeting and tell your IPP team that you want SLS. Ask for a decision-maker who knows about SLS to be at the IPP meeting. (To see a sample letter to ask for an IPP meeting, see Supplement N.)

Some regional centers will ask you to go to an SLS orientation before the IPP meeting. This can help you understand more about SLS and how it is provided. But going to the orientation should not delay your IPP meeting for too long.

Regional centers have different ways to calculate the cost of SLS and the DDS “cost-cap.” Some regional centers will try to keep SLS out of your IPP if they believe the cost is more than the “cost-cap.” Others wait until the SLS plan is complete to look at the “cost-cap.”

***Important!*** The regional center cannot stop you from receiving SLS because of a “cost-cap.” (See *Question 12 above.*)

Once SLS is in your IPP, you will need to choose an SLS provider (vendor). You have several options:

You may recommend a relative, friend, or an SLS provider you know. Or you may want to do it yourself.

You may ask the regional center for names of SLS agencies. You can interview them to decide which agency you prefer. (*Supplement O has suggestions on how to interview an SLS agency.*)

If you give your permission, the regional center may send some information about you to several SLS agencies to see who is interested in serving you. Then you can interview those agencies.

Once you select the SLS provider you prefer, the regional center should arrange for you to have an SLS assessment. The assessment is usually

done by the SLS provider you selected. But some regional centers will have someone else do the assessment.

The SLS assessment usually takes quite a bit of time, as you and the assessor must get to know each other. The assessor will look at the services and supports you prefer and need to live in your own home and be integrated into your community. The assessor will propose an SLS plan, in writing. (This is often called an Individual Support Plan or ISP.) The ISP explains the services and supports you need. And, it shows how much the SLS plan will cost to provide.

Once the SLS plan is complete, you, the regional center, the SLS vendor, and other people who can help you get started will probably have another IPP meeting. If the SLS plan is approved, the SLS agency will help you find a place to live, find roommates (if you want and need them), and hire personal support people.

***Plan ahead!*** It may take about six months from the time you first ask for SLS until you can move into your home.

#### **14. If I get SLS, do I have to live with other people?**

Not necessarily. You may want to:

Have a roommate who is a friend (with or without a disability), or

Have a roommate who is paid by your SLS agency to provide support,  
or

Live alone.

Just like any person trying to rent a home, you may want or need a roommate to share expenses so you can have a nicer place to live and have money left over for other expenses. You must decide what is best for you.

#### **15. Can I receive emergency or crisis intervention services in my supported living arrangement?**

Yes.<sup>25</sup> See Chapter 1, Question 11 for more information on emergency and crisis services.

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<sup>25</sup> § 4648(a)(10).

## 16. What is a Bates Home?

A Bates Home is a foster care home for children with special health care needs.<sup>26</sup> Parents do not have to give up their parental rights if their child lives in a Bates Home.

A Bates Home can be:

- A small family home,
- A licensed foster family home, or
- A foster family home certified by a licensed Foster Family Agency (FFA).

These are all foster homes where the foster parents live in the home and have been trained to provide specialized in-home health care to foster children.<sup>27</sup> The foster parents work closely with the child's Individual Health Care Plan Team. This team includes doctors, regional center staff, and any other health professionals involved in the child's treatment.<sup>28</sup>

To be eligible for a Bates Home, the child must:

Be between 0-22 years old,

Be enrolled in a public education program, and

Have a special health care need that can quickly deteriorate or a condition that requires specialized in-home health care, including any service that the child's primary physician says should be provided at home by someone trained by health care professionals, such as:<sup>29</sup>

enteral feeding tube or total parenteral feeding (TPN),  
cardiorespiratory monitor, ventilator or oxygen support,  
intravenous therapy,  
urinary catheterization,  
renal dialysis,

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<sup>26</sup> § 17710(i).

<sup>27</sup> § 17710(h)(1).

<sup>28</sup> § 17710(d).

<sup>29</sup> § 17710(a). Bates Homes are available for regional center consumers who meet the remaining requirements.

tracheostomy, colostomy, ileostomy, or other medical or surgical procedures or special medication regimens, including injection, and intravenous medication.<sup>30</sup>

In 2005, about 45 children with developmental disabilities lived in Bates Homes.

### **17. What is a Foster Family Agency home placement?**

A child with developmental disabilities can live with a specialized foster family through a Foster Family Agency (FFA) home placement. This is not like traditional foster care, as the foster family is certified by the FFA and has training and supports from the FFA to help a child who has special needs because of a developmental disability.<sup>31</sup>

Many people believe that FFA homes and Bates Homes are more appropriate for children than a group home because they provide a family setting and are more similar to the way children without disabilities live.

Parents do not have to give up their parental rights if their child lives in an FFA-certified foster home.

By 2005, about 420 children with developmental disabilities had lived in FFA-certified homes.

### **18. What is an Adult Family Home Agency (AFHA)?**

Adult Family Home Agencies are private, not-for-profit agencies. Regional centers contract with AFHAs to develop homes for adults who want to live with a family.<sup>32</sup> After getting trained and with some continuing help from the AFHA, a family can take in one or two adults with developmental disabilities to live with them as part of their family.<sup>33</sup>

The AFHA model was established in 1994 to provide a new cost-effective living option for adults. This option allows adults to enter into partnerships with families as fully participating family members. The regional center contracts with the AFHA to recruit and train families,

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<sup>30</sup> § 17710(g).

<sup>31</sup> § 17710(i)(3).

<sup>32</sup> § 4689.1; Cal. Code Regs., tit. 17 § 56078(a).

<sup>33</sup> § 4689.1(b).

certify family homes, match individuals and families, provide ongoing support to families, and monitor family homes.<sup>34</sup>

AFHAs are not licensed, but the quality is monitored by regional centers and DDS.<sup>35</sup> Regional center staff visit the family home at least four times each year and evaluates the AFHA annually. Periodically DDS evaluates how well the AFHAs and the regional centers are performing.

If you live in an AFHA home, you will usually have the same kinds of chores and responsibilities as other family members. There is supervision for non-medical self-care and daily living skills, if you need it. You will get the support and services you need from the family, AFHA, and the regional center.

By 2005, about 375 people with developmental disabilities had lived in Adult Family Homes.

## **19. What is a Family Teaching Home?**

A Family Teaching Home is a new kind of living arrangement for adults.

It is different from an AFHA in two ways:

The family and the person(s) with a disability do *not* share the same private home. The teaching family lives in a home adjoining the home of the individual(s), usually a duplex that is owned, leased, or rented by the AFHA.

The Family Teaching Home is designed to support up to three adults with any kind of developmental disabilities who do not need continuous skilled nursing care.

The teaching family has these responsibilities:

They must be certified and trained by the AFHA, get additional training throughout the year, and renew their certification annually.

They provide support and supervision for the people with disabilities.

They manage the adjoining home, provide direct support, and directly supervise any staff that work for them when they are not available.

The Family Home Agency must provide or arrange the services and supports that the people with disabilities need, including work and other program supports.

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<sup>34</sup> Cal. Code Regs., tit. 17, § 56076(e)(6).

<sup>35</sup> Cal. Code Regs., tit. 17, § 56095(g).

Family Teaching Homes worked successfully in Kansas. And in 2004, our state laws were changed to include this as an option.<sup>36</sup> Just like AFHAs, Family Teaching Homes are certified, monitored, and evaluated by the regional center and DDS.

Several Family Teaching Homes have been started in the Bay Area as part of the Agnews Developmental Center Closure Plan. The law allows any regional center to start a Family Teaching Home. If this living arrangement seems attractive to you, ask your regional center about starting a Family Teaching Home.

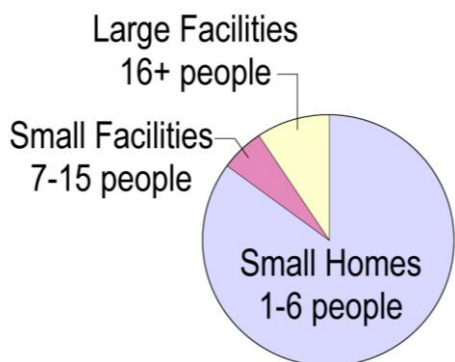
## 20. What types of group living arrangements are available?

Most people with developmental disabilities who live outside their families' homes live in group homes or facilities. There are three different kinds of group settings:

**Homes** with up to 6 people with developmental disabilities,  
**Small facilities** with 7–15 people with developmental disabilities, and  
**Large facilities** with more than 16 people with developmental disabilities.

All of these group living arrangements must have a special license from the Department of Health Services (DHS) or the Department of Social Services (DSS). DHS calls them Community Care Facilities, or CCFs for short; DDS calls them Intermediate Care Facilities, or ICFs for short.

In 2005, about 30,000 people with developmental disabilities lived in group living arrangements. **Most** of them lived in small homes. The chart below shows which kinds of group arrangements people chose.



### Group Living Arrangements in 2005

86% lived in small homes

9% lived in large facilities (called ICF-DDs or CCFs) with 16 or more residents

5% lived in small facilities (called ICF or CCF) with 7-15 residents

<sup>36</sup> § 4689.1(c).

*See Questions 21 – 29 for more information on CCFs and ICFs.*

## **21. Is there more than one kind of small home CCF?**

Yes. There are several different small home CCFs. A system, called ARM,<sup>37</sup> categorizes each CCF by the level of care they provide. The ARM system looks at staffing ratios, the amount of consultant services, and the needs of the residents, and ranks each CCF as ARM Level 2, 3 or 4. The amount of funding the CCF gets depends on its ARM Level.<sup>38</sup>

ARM Level 2 has the lowest staffing ratio. This means the people who live there need fewer supports and services.

ARM Level 4 has the highest staffing ratio. Level 4 also has 9 sub-levels, ranging from A to I. This means the people who live there need more supports and services. Often ARM Level 4 serves people with challenging behaviors.

Each ARM facility must have a description of its programs and information about how its services meet the requirements of its residents' IPPs.<sup>39</sup>

## **22. Are there CCFs that do not have ARM Level classifications?**

Yes. Some regional centers have small, specialized CCFs. The regional centers run them at negotiated rates. They usually have 1-4 people with more complex needs. These CCFs are not part of the ARM Level system.

These homes are generally developed as part of the regional center's Community Placement Plans. The people who live there may be moving out of, or diverted from, a developmental center.

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<sup>37</sup> CCF group living arrangements are also given different names and have different requirements in DSS licensing statutes and regulations depending on whom they serve. Children's CCFs are called Small Family Homes or Group Homes. CCFs for people aged 18-64 are called Adult Residential Facilities. CCFs for people 65 and older are called Residential Care Facilities for the Elderly. Health & Safety Code § 1502(a), 1530 et seq., Cal Code Regs, tit. 22 §§ 87100-87731.4.

<sup>38</sup> § 4681.1 and Cal. Code Regs., tit. 17 § 56004 set forth specific staffing and consultant hour requirements.

<sup>39</sup> § 4681.1; Cal. Code Regs., tit. 17 § 56013.

These specialized homes serve people with unique mental health and behavioral challenges whose needs cannot be appropriately met by other community living options. Generally, they provide 24-hour on-site specialized staff and professional services to meet the specific needs of their residents. Often, these homes can respond to on-site crises to meet scheduled or unpredictable needs in a way that promotes maximum dignity and independence.

### **23. Are there CCFs for people with specialized health care needs?**

Yes. There is a new kind of small CCF, called Adult Residential Homes for Persons with Specialized Health Care Needs. This kind of living arrangement is also called an **SB 962 Home**. (It was named for the Senate bill that authorized the homes).<sup>40</sup>

This kind of home was designed to meet the unique needs of people with developmental disabilities who have a combination of specialized health care and intensive support needs. Each SB 962 home serves up to five people. A resident of an SB 962 home can receive many specialized health services, including:

nutritional support (total parenteral nutrition (TPN), gastrostomy feeding, and hydration),  
kidney dialysis, and  
special medication regimes, such as injections, intravenous medications, management of insulin dependent diabetes, catheterization, indwelling urinary catheter management, pain management, and palliative care.

All SB 962 homes must have:

Licensed nurses on staff 24 hours a day, seven days a week.

An Individual Health Care Plan developed especially for each resident.  
(The plan must be updated at least once every six months.)

Face-to-face visits with the resident by a regional center nurse at least once a month.

The SB 962 homes are a pilot project in the Bay Area. They provide community-based services for up to 120 current Agnews Developmental Center residents. DDS and DSS Community Care

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<sup>40</sup> §§ 4684.50, 4684.73, 4684.74, 4684.75 and Health & Safety Code §§ 1538.55, 1567.50.

Licensing Division are working together to create a regulatory oversight plan for this new licensing category. An independent evaluation of this type of living arrangement will be submitted to the Legislature by January 1, 2009.

#### **24. What is the main difference between a CCF and an SB 962 home?**

People who live in CCFs can *only* receive limited medical services from the staff, including:

- gastrostomy feeding and care,
- care of urinary catheters, and
- care of colostomy and ileostomy bags.<sup>41</sup>

There are also limitations on the type of medical care that regional center consumers may receive from staff at a CCF.<sup>42</sup> If a resident needs medical care from a health care professional, a doctor or nurse will go to the home. Or the resident may be taken to the doctor or nurse.

Because of these limitations on medical care in CCFs, Disability Rights California believes that California needs SB 962 homes in all parts of the state. Disability Rights California also believes that SB 962 homes should be accessible to people who do not currently live in Agnews or other developmental centers. Disability Rights California hopes the Legislature will make more SB 962 homes available as soon as possible.

#### **25. How many people live in CCF homes?**

It can vary. Many small home CCFs have six residents. Usually residents share a bedroom with one other person. However, today, many regional centers are developing CCF homes for four or fewer residents where each person has his or her own bedroom.

If you want to live in a smaller home and have your own bedroom, ask for a small home CCF at your IPP meeting.

Some CCFs are large homes that serve over 16 people. Usually these are large homes that are set up like an institution. Most people prefer the smaller models.

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<sup>41</sup> Health & Safety Code § 1507.

<sup>42</sup> Health & Safety Code § 1507(c)(1).

Question 29 talks about the possibility of “downsizing” large CCFs.

**26. What happens if the facility I live in says I must leave because of my behavior?**

The law says that regional centers must provide the emergency and crisis intervention services you may need to stay in your chosen living arrangement.<sup>43</sup>

This means the home or facility where you live should provide crisis intervention services, including mental health and behavior modification services. The regional center can also provide extra staff in your group living facility. If your behavior cannot be handled in that setting, you must be allowed to go to emergency housing in your home community.

If this happens to you, the regional center must do everything possible to get you back to your chosen living arrangement, with all needed supports, as soon as possible.

See Chapter 1, Question 11 for more information on emergency and crisis services.

**27. Where in the community can a small CCF home be located?**

A small CCF can be located in the same areas as any other family residence. State law says that CCFs with 6 or fewer people must follow the same zoning and municipal regulations as any other family home, even if the residents are not related to each other.<sup>44</sup>

**28. What kinds of intermediate care facility (ICFs) are there?**

There are four different kinds of ICFs:

- ICF/DD
- ICF/DD-Habilitation
- ICF/DD-Nursing
- ICF/DD-Continuous Nursing

All of them are facilities where people with developmental disabilities live and receive the health care services, life skills training and

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<sup>43</sup> § 4648(a)(10).

<sup>44</sup> *E.g.*, § 5115(b); Health & Safety Code §§ 1566.2, 1566.3.

habilitation (vocational training) they need. Because they provide some nursing/medical care on site, ICFs are licensed by the Department of Health Services and are regulated by Health and Safety Code licensing provisions.<sup>45, 46, 47</sup>

Most ICFs are small, with 6 or fewer residents. But ICFs can be larger, sometimes with up to hundreds of residents. Here's a summary:

**ICF/DD Institutions** — These are large institutions that serve 16 or more people with similar needs. They provide mostly developmental services, and periodic skilled nursing services.<sup>48</sup>

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<sup>45</sup> Federal Medicaid law provides that ICF-DD (federal government calls the category ICF-MR) facility services are available to persons who are mentally retarded or have a related condition as defined by the Centers for Medicare and Medicaid Services (CMS). However, California's ICF-DD regulations limit admission to those who meet the state service definition of developmental disability at Welf. & Inst. Code section 4512(a). The CMS Medicaid definition of mental retardation and related condition at 42 C.F.R. section 435.1009 is broader than the state service definition of developmental disability in two ways: first, it includes persons who became disabled prior to age 22 rather than prior to age 18; second, it includes persons whose adaptive deficits are the result of a neurological or other impairment without necessarily involving any impairment of cognitive functioning. The primary group excluded from California's ICF-DD facilities that would be included under the CMS definition are persons with traumatic brain injury whose injury occurred between ages 18 and 22. Disability Rights California contends that the state does not have the authority to exclude from ICF-DD facilities those who need those services and meet the federal CMS Medicaid definition of mental retardation and/or related conditions. In *Brain Injury Policy Institute (BIPi), et al v. Shewry*, San Francisco Superior Court Case No. F049390-A, filed in 2006, Disability Rights California along with other public interest groups are challenging the exclusion.

<sup>46</sup> An "[i]ntermediate care facility/developmentally disabled habilitative' means a facility with a capacity of 4 to 15 beds that provides 24-hour personal care, habilitation, developmental, and supportive health services to 15 or fewer developmentally disabled persons who have intermittent recurring needs for nursing services, but have been certified by a physician and surgeon as not requiring the availability of continuous skilled nursing care." Health & Safety Code § 1250(e); see also, §§ 1250(g) and 1250(h). Because Medi-Cal is the primary payor, Medi-Cal regulations set out admission criteria and scope of services provided. See Cal. Code Regs., tit. 22 §§ 51343 (ICF-DD), 51343.1 (ICF-DDH), 51343.2 (ICF-DDN). Per 42 U.S.C. § 1396d(d), the federal requirements for ICF-DD (the federal designation is ICF-MR) are set out at 42 C.F.R. §§ 483.400-483.480.

<sup>47</sup> Health & Safety Code §§ 1250(e), (g), (h); Cal. Code Regs., tit. 22 §§ 73800-73956 (ICF-DDN), 76000-76725 (ICF-DD), 76800-76962 (ICF-DDH).

<sup>48</sup> Health & Safety Code § 1250; Cal. Code Regs., tit.17, § 54302(a)(41).

**ICF/DD-Habilitation Homes** — Most are small homes for 6 people, but they can house up to 15 people.<sup>49</sup> They provide 24-hour personal care, developmental and vocational training, and supportive health care.

**ICF/DD-Nursing Homes** — Most are small homes for 6 people, but they can house up to 15 people. They provide 24-hour personal care, nursing supervision, and periodic nursing care on-site for up to 8 hours per day for people with ongoing medical needs<sup>50</sup> or significant developmental delays that may lead to a developmental disability if they do not get the care they need.

**ICF/DD-Continuous Nursing Homes** — This is a pilot program and there are very few of them. They serve 1-6 residents and provide skilled nursing care 24/7 from (or supervised by) a registered nurse.<sup>51</sup> If there were more ICF/DD-Continuous Nursing homes, it would help people who are in institutions to move to this kind of home.

This table gives you information about the different kinds of ICFs.

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<sup>49</sup> Health & Safety Code § 1250(e); Cal. Code Regs., tit.17, § 54302(a)(42).

<sup>50</sup> Health & Safety Code § 1250(h); Cal. Code Regs., tit. 17, § 54302(a)(43).

<sup>51</sup> § 14495.10.

<b>ICF/DD Institutions</b>	
Large institutions with 16+ people with similar needs	mostly developmental services, and periodic skilled nursing services
<b>ICF/DD-Habilitation Homes</b>	
Mostly small homes for 6 people (but can house up to 15)	24-hour personal care, developmental and vocational training, and supportive health care
<b>ICF/DD-Nursing Homes</b>	
Mostly small homes for 6 people (but can house up to 15)	24-hour personal care, <ul style="list-style-type: none"> <li>■ nursing supervision, and</li> </ul> periodic nursing care on-site for up to 8 hours per day (for people with ongoing medical needs or significant developmental delays that may lead to a developmental disability if untreated.)
<b>ICF/DD-Continuous Nursing Homes</b>	
This is a pilot program and there are very few of them. They serve 1-6 residents.	skilled nursing care 24/7 from (or supervised by) a registered nurse  More ICF/DD-Continuous Nursing homes are needed so people in institutions could move to this type of home.

**29. Is the state trying to “downsize” large CCFs and ICFs?**

The Department of Developmental Services has funds that can be used to “downsize” large CCFs or ICF-DDs (with 16 or more residents). Regional centers can use these funds to contract with a large CCF or ICF-DD that is interested in reorganizing so it can serve people in smaller home settings.

Consumers and advocates should ask the regional centers to work with large residential providers to use these “downsize” funds. This would

help more people move out of large institutions into smaller, home-like living arrangements.

### **30. What is a developmental center (DC)?**

Developmental centers are the most restrictive kind of living arrangements for people with developmental disabilities. They are large, state-run institutions for people with developmental disabilities. Many units at DCs are “secure,” or locked.

Developmental centers are only for people who cannot get the health care or behavioral treatment they need in any other kind of facility.

If you are an adult, you cannot be *forced* to live in a DC, unless there is a court order that:

Is based on Welfare and Institutions Code § 6500 *et seq.*

Is based on an “*In Re Hop*” procedure (see *In RE Hop*, 29 Cal.3d 82)

Is in connection with a criminal violation (Cal. Penal Code § 1307.1)

Children, under 14, may be “voluntarily” admitted to a DC if their parent or guardian agrees. If the child is 14 or older, they have additional due process rights.<sup>52</sup>

Many people who live in developmental centers today *could* be served appropriately in community living arrangements. We expect fewer people to enter developmental centers each year because more people will find an appropriate placement in a less restrictive setting that is more closely connected to the community.<sup>53</sup>

For information about how to avoid being placed in a DC or how to move out of a DC, see Chapter 9.

### **31. What is a nursing facility (NF)?**

A nursing facility gives patients skilled nursing care and supportive care on an extended basis.<sup>54</sup> However, you can get many of the same

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<sup>52</sup> *In re Roger S.*, 19 Cal.3d 921 (1977).

<sup>53</sup> People who move from a developmental center into a community home have the right to return to the developmental center if they wish or if their conservator wishes, within twelve months of the provisional placement. § 4508.

<sup>54</sup> Health & Safety Code § 1250.

supports and services found in a NF in a more community integrated living arrangement.

Most NFs are large institutions that serve elderly people with a variety of disabilities that require nursing care. NFs are only allowed to accept a few people with developmental disabilities. This means that the residents with developmental disabilities are younger than the other residents. In 2005, almost 1400 regional center consumers lived in NFs.

You do not *have to* live in an NF if you do not want to. If you live in a NF, you can ask your service coordinator to help you find another living arrangement that meets your needs. If the regional center says there is no such living arrangement available, you can ask them to develop a special living arrangement that meets your specific needs.

**Caution:** You may have to wait until either the ICF-DD-CN homes or SB 962 homes are allowed to expand beyond pilot project status. See Question 25 and 28 above. You may also want to ask your service coordinator to help you get on the waiting list for the Home and Community Based Nursing Facility Waiver. (*For more information, see Chapter 13.*)

### **32. Are there nursing facilities for people with psychiatric disabilities?**

Yes. They are called Institutes for Mental Disease (IMDs). In 2005, about 65 regional center consumers lived in this kind of nursing facility.

### **33. What is a sub-acute facility (SAF)?**

Sub-Acute Facilities are for patients who do not need to be in a hospital, but who need more intensive care than they can get in a regular nursing facility (NF).<sup>55</sup> Usually, they are large institutions. Some SAFs serve only children. These are called Sub-Acute Pediatric Facilities.

In 2005, about 238 regional center consumers lived in Sub-Acute and Sub-Acute Pediatric Facilities.

You should not *have to* live in an SAF if you do not want to. If you live in an SAF, you can ask your regional center to help you find another living arrangement that meets your needs. If the regional center says there is no community option available, you can ask them to develop a special living arrangement just for you.

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<sup>55</sup> Cal. Code Regs., tit. 22, § 51124.5(a).

**34. Are there specialized living arrangements for people with dual diagnosis of developmental and psychiatric disabilities?**

Yes. See Chapter 10 on services for people with dual diagnosis.

**35. What is a community treatment facility?**

A community treatment facility (CTF) is the highest level of community care facility for seriously emotionally disturbed children and youth.<sup>56</sup> CTFs are licensed by the Department of Social Services and certified by the Department of Mental Health as mental health programs. CTFs have locked units.

**36. What happens if the living arrangement I want is not available?**

Sometimes the type of living arrangement that you and your planning team have agreed on is not available. This could be because:

There is no space at the home or facility,

There is no one available to provide the supported living services you need, or

There is no Foster Family or Adult Family Home available in the area where you want to live.

Depending on the type of living arrangement your IPP specifies and the reason why it is not available, the regional center staff can do a number of things to develop the living arrangement you want. However, this may take time. Meanwhile, you may need to move to a less-favored living option or to a home or facility away from your home community.

If this happens to you, the law says that you can ask your regional center to:

Seek out individuals or agencies to provide the services you need. This process is called “request for proposal” (RFP).<sup>57</sup> If the supports and services you need are unique, the RFP can say that the regional center can make a special funding agreement. For example, if you need a group home with only one other resident and three staff with easy access to crisis services, the regional center’s RFP will describe your unique needs and the amount it is offering to pay for the needed services.

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<sup>56</sup> Welf. & Inst. Code § 4094.5.

<sup>57</sup> § 4648(e)(1).

Hire a vendor to provide the services you need. If a rate has not been established by DDS, the regional center may negotiate a contract for the service you need for an interim period of time.<sup>58</sup>

Provide supplemental services, including additional staffing beyond the service provider's current contract, if your IPP team determines the additional services are consistent with your IPP.<sup>59</sup>

You should *not* have to go to a developmental center or other institution just because there is no community living arrangement available.

***Important!*** If you are now in a community living arrangement that is not working, and you are at risk of being admitted to a developmental center (DC), your regional center or your parents can ask for special "deflection" procedures. Deflection procedures involve taking immediate action so you can stay out of the DC. For example, the regional center can ask the Regional Resource Development Project for emergency services to place you in a crisis home or to hire additional staff in your current home (if your IPP team agrees that it is needed).<sup>60</sup>

For more information about how to avoid placement in a DC, see Chapter 9.

### **37. If my child is under 18, but cannot stay in my home, how can I make sure that he or she stays nearby?**

The Lanterman Act says it is very important for children to stay in their family homes<sup>61</sup> or to keep them near their families if they cannot live in the family home.

The law says that regional centers must make every effort to find a living arrangement for a child under age 18 that is reasonably close to the family home.<sup>62</sup>

When the regional center cannot find a home close to the family home, the child's IPP must say:

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<sup>58</sup> § 4648(a)(3).

<sup>59</sup> § 4648(a)(6)(C).

<sup>60</sup> §§ 4418.7, 4648(a)(10), 4648(a)(6)(C).

<sup>61</sup> § 4685(c).

<sup>62</sup> § 4685.1.

What the regional center has done to find, develop, or adapt appropriate services and supports in a living arrangement nearby, and

What steps the regional center will take to develop the services and supports the child needs to return to the family home or to a setting near the family home.

The regional center must update their statement about what is being done every six months and send a copy to the family and the director of DDS.<sup>63</sup>

### **38. Do families have to pay for out-of-home placements of a child under 18?**

Yes. The law says that families can be charged for out-of-home placement of their children up to the age of 18.<sup>64</sup> The fees must be based on the family's ability to pay, and the fees cannot be more than the cost of caring for a non-disabled child at home, or the cost of the services provided, whichever is less.<sup>65</sup>

For information on how charges are calculated, see Chapter 1, Question 22.

### **39. Do people who live in a developmental center or other licensed residential facility have rights?**

Yes! You have important rights. And, the staff at your living arrangement must tell you about them when you arrive. They must explain your rights in a way that you can understand. They must also post your rights in simple, clear language and pictures at the facility. A list of your rights must be available on tape, in Braille, in English, Spanish, and other appropriate languages.

You have these rights when you live in a licensed home or other facility:<sup>66</sup>

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<sup>63</sup> § 4685.1(b).

<sup>64</sup> § 4782. Disability Rights California believes that if the placement is paid for by Medi-Cal, the parents cannot be charged for the cost of care. See Chapter 1, Question 22.

<sup>65</sup> Cal. Code Regs., tit. 17, §§ 50221 et seq.

<sup>66</sup> § 4503.

- To wear your own clothes and to keep your own personal belongings, including toothpaste, deodorant, and lotion.
- To keep and to spend a reasonable amount of your own money for small purchases. That money is sometimes called P&I money (for personal and incidental expenses). It should be available to you when you want to spend it.<sup>67</sup> If you have more than a small amount of money, the residential facility staff must keep your money safe and separate from anyone else's money.
- To have access to an individual storage space for your things for your private use. If the storage place is locked, you have a right to have it opened whenever you want to use it.<sup>68</sup>
- To see visitors each day. Where you are living is your home, and you have the right to have guests.<sup>69</sup>
- To reasonable access to the telephone, and to make and receive private and confidential calls. No one can listen in on your calls.<sup>70</sup>
- To have ready access to letter writing materials, including postage stamps, and to send and receive letters unopened.<sup>71</sup>
- To refuse electroconvulsive (electroshock) therapy.<sup>72</sup>
- To refuse behavior modification techniques that cause pain or trauma.<sup>73</sup>
- To refuse psychosurgery (operations such as lobotomy, psychiatric surgery or behavioral surgery) and any other brain or thought modification surgery.<sup>74</sup>
- To make choices in your daily living routine, including who you want to spend time with, how to use your leisure time, and social activities. You also have the right to plan and implement your IPP.<sup>75</sup>

#### **40. Can my rights be taken away from me?**

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<sup>67</sup> § 4503(a).

<sup>68</sup> § 4503(b).

<sup>69</sup> § 4503(c).

<sup>70</sup> § 4503(d).

<sup>71</sup> § 4503(e).

<sup>72</sup> § 4503(f).

<sup>73</sup> § 4503(g).

<sup>74</sup> § 4503(h).

<sup>75</sup> § 4503(i).

These rights can **never** be taken away:

To refuse electroshock therapy.

To refuse painful or traumatic behavior modification techniques.

To refuse brain or thought modification surgery.

To make choices in your daily living routine, including who you want to spend time with, how to use your leisure time, and social activities.

To plan and implement your IPP.

But if there is “good cause,” rights 1–6 listed above (see *Question 39*) may be taken away in certain situations.<sup>76</sup>

Only the professional person in charge of your home or facility can take away those rights, and only if that person determines that:

You or someone else at the facility will be injured, or that facility property will be damaged,

There is no less restrictive way to protect you or other residents, and

The right(s) denied is related to the solution of the problem in question.

For example, no one can deny your right to have visitors because you forgot to clean up the kitchen. (The two things are not related.)

But they can deny your right to have a visitor if that person has hurt other residents. (These two are related.)

If the professional person decides to deny your right(s), s/he **must**:

Describe in writing the event that resulted in the denial of your right(s) within 24 hours.

Send this information to your clients’ rights advocate, who must review it to make sure the facility followed these rules.<sup>77</sup>

No one can deny you your rights as a way to punish you. A right is not a privilege that must be “earned.” If someone takes away your right(s), that decision must be reviewed at least every **30 days**. If good cause no longer exists, the facility must return your right immediately.<sup>78</sup>

#### **41. Are there rules that licensed homes and facilities must follow?**

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<sup>76</sup> § 4504.

<sup>77</sup> Cal. Code Regs., tit. 17, § 50536.

<sup>78</sup> Cal. Code Regs., tit. 17, § 50530(f).

Yes. All licensed homes and facilities, including developmental centers, ICFs and CCFs, must follow California law and regulations. The rules and standards that are based on the law help keep everyone safe. Many of the rules are complex and technical – from the size of doorways to the amount of food the facility must always have.

Community Care Licensing and Health Services Licensing are responsible for enforcing the rules and regulations about the care residents must receive. But, much of the responsibility for checking on the quality of services provided to consumers in community residential facilities falls upon the regional center.

Quality assurance is one of the most important duties of the regional center. The Department of Developmental Services must insure the quality of services in developmental centers. If you have concerns that the regional center or DDS are not adequately monitoring a residential facility, speak with your service coordinator, the Clients' Rights Advocate, or the Area Board.

#### **42. What are house rules?**

All licensed community living arrangements and day programs (including CCFs and ICFs) have “house rules.” The house rules explain what you can and cannot do. The facility must explain the rules to you when you arrive or start the program. They must post the rules so you can see them, and they must be written in a language you understand.

You have the right to make decisions about daily activities, including when you go to bed, when you will eat, whether to have friends visit, and what you do in your free time. The rules should help people in the house get along with each other, but they cannot be too rigid. For example, a rule saying everyone must be in bed by 10:00 p.m. is illegal. A rule saying all radios and TVs must be turned off after 10:00 p.m. is also too rigid and not reasonable. But a rule that says you should use earphones while your roommate is sleeping *is* reasonable. This allows you to listen to your radio without disturbing your roommate.

***Important!*** The rules must be reasonable and must not violate any of your rights. If you believe your facility has an illegal rule, you can call the Clients' Rights Advocate at your regional center. You can also file a complaint against the facility. (See *Chapter 12, Questions 37-38.*)

### **43. Can I be evicted from my residential facility?**

Maybe. The facility can evict you, or force you to leave, in certain situations. For example, they can evict you if the facility decides that:

They can no longer meet your needs,

You pose a threat to other residents, or

You do not comply with reasonable house rules.

The rules for eviction are complicated. They may depend on the type of facility you live in and the reason the facility wants you to leave. If your facility asks you to leave, but you want to stay, call your regional center service coordinator. Like any tenant, you have rights related to an eviction.

For more information and advice, call OCRA or the Disability Rights California office in your region. You can ask Disability Rights California for publication 5316.01, *Eviction Rights of Community Care Facility Residents*.