

RIGHTS UNDER THE LANTERMAN ACT

Supports and Services That Keep Families Together

Chapter 6

This chapter explains:

- Services and supports that keep families together,
- Respite services and other family supports,
- Supports for adults living in family homes,
- Supports for adopted and foster children, and
- Behavioral support



Chapter 6: Supports and Services for Adults and Children Living at Home

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Chapter 6

Services and Supports that Keep Families Together

This chapter gives you answers to the most common questions about services and supports for children and adults with developmental disabilities who live at home. We explain how the law supports keeping families together.

You will also learn about:

- *Services and supports that keep families together,*
- *Respite services and other family supports,*
- *Supports for adults living in family homes,*
- *Behavioral supports.*

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. We have listed the exact section of this state law where the information is found. When you see § 4512(a), for example, it means that 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>

1. What services and supports can I get if I live with my family?

The Lanterman Act says that helping children under 18 to stay in their family home is a high priority.¹ Many adults with developmental disabilities live with their parents or other relatives. If you live with your family, you have the right to:

- services that support you, and
- services that support your family.

For more information on staying in your family's home, see Question 3.

¹ § 4685. All references in this manual are to the Lanterman Act unless it says otherwise. The § symbol means "section."

The services and supports you receive depend on what you (and your family) need and want.² Your Individual Program Plan (IPP) process determines the services you get. For more on the IPP process, see Chapter 4.

All of your regional center services and supports should help you be more independent and live like people of your same age without disabilities. You should receive your services in the most integrated, inclusive settings possible.³

To learn about other types of support you can receive, see Chapter 7.

2. What does the law say about children with developmental disabilities who live with their families?

The Lanterman Act recognizes that most children under 18 have more opportunities for educational and social growth if they live with their families.⁴ Because of this, the law says it is very important to develop and expand services for families with children with developmental disabilities.⁵ The law also says it is important to respect and support the family's decisions.⁶

Your IPP should include a "family plan component" that talks about the services and supports you need to stay in your family's home. Regional centers must consider *every possible way* to help families keep their children at home if living at home is best for the child, before considering other options that require the child to leave the family home.⁷

If the regional center finds out that out-of-home placement is being considered, it must promptly meet with the family to figure out how to keep the family together.⁸ Parents do not have to ask for out-of-home placement or start the placement process to receive the services and supports they ask for.⁹

² §§ 4512(b); 4646(a) and (e).

³ § 4502.

⁴ § 4685(a).

⁵ § 4685(a).

⁶ § 4685(b)(1).

⁷ § 4685(c)(2).

⁸ § 4685(c)(2).

⁹ § 4685(c)(4).

3. What if the regional center is not doing enough to help keep my child at home?

If you believe the regional center is not doing enough to help you keep your child at home, ask for an IPP or IFSP meeting and tell them you need more help. If you do not agree with the regional center about the supports your family needs, you can ask for a hearing.¹⁰

For a sample letter to ask for an IPP meeting, see Supplement N.

Use the IPP/IFSP Meeting Planner in Supplement L to help you decide which services you need to keep your child at home.

For more information on appeals, see Chapter 12.

4. What does the law say about family supports?

If you have a developmental disability and live with your family, the regional center:

- Must be flexible and creative to meet your needs (and your family's needs), as they change over time.¹¹
- Must respect your family's cultural preferences, values and lifestyle.¹²
- Should recognize and build on your family's strengths, natural supports and the resources already available in the community.¹³
- Should provide family support services that promote your inclusion in all aspects of school and community.¹⁴

5. What kinds of family support services can I get?

Here are some of the services and supports you can get if you have a developmental disability, live with your family, and meet certain criteria. Most of the services listed are for children and adults.

- Special training for parents of children with developmental disabilities and parents with developmental disabilities. (See Question 44 below.)

¹⁰ § 4685(c)(4).

¹¹ §§ 4685(b)(2); 4648(a)(2).

¹² § 4685(b)(4).

¹³ § 4685(b)(3).

¹⁴ § 4685(b)(5).

- Adaptive equipment like wheelchairs and hospital beds. See Disability Rights California's publication 5320.01, *Accessing Assistive Technology Manual*. You can get it from Disability Rights California or OCRA.
- Advocacy (including training to advocate for yourself), facilitation, peer advocates, and help getting welfare, educational services and other public benefits, such as California Children's Services (CCS), In-Home Supportive Services (IHSS), Supplemental Security Income (SSI) and Medi-Cal. (See Chapters 4 and 5.)
- Behavior training and behavior modification programs. (See Questions 44-47 below.)
- Camping. (See Chapter 8, Question 61)
- Communication devices and other appliances and supplies you need. (See Question 35 below.)
- Community integration services. (See Chapter 8, Question 2.)
- Counseling.
- Day Care. (See Questions 30–33 below.)
- Diapers. (See Question 17 below.)
- Emergency and crisis intervention. (See Question 39 below and Chapter 1, Question 11.)
- Facilitating circles of support. (See Chapter 4, Question 11.)
- Early intervention programs, like infant stimulation. For more information on early intervention programs, see Chapter 12 of Disability Rights California's publication 5040.01 - *Special Education Rights and Responsibilities*. You can get it from Disability Rights California or OCRA.
- Mental health services. See Chapter 10 on services for people with both developmental and psychiatric disabilities.
- Respite for caregivers, either in or out of the home. (See Questions 18-26 below.)
- Social skills training. (See Question 35 below.)

- Specialized medical and dental care.

Transportation to make sure that people with developmental disabilities receive their services. Children no longer will receive regional center funding for transportation, unless the family can prove that it cannot provide transportation. (See Question 14, below. See also Chapter 8, questions 62 and 63 for more information on transportation services.)

- For a more complete list of regional center services, see Supplement C.

6. When should I ask for services and supports?

Ask for services at your first IPP planning team meeting and whenever you need more or different services. As soon as the regional center finds out that your family needs more services to keep a child at home, it must meet with your family to discuss the situation.

The law says that regional centers must investigate and meet your family's needs in creative and innovative ways so you will have the support to keep your family together.¹⁵ If the family needs change, and you need different supports and services, you also need a new IPP. Use the method described in Chapter 4 to prepare your IPP. To help you decide what to ask for, see the IPP/IFSP Meeting planner in Supplement L.

7. Are there different services or processes for children under three?

Yes. Services for children under three are called *Early Start* or *early intervention* services. Most of these services are covered by Part C of the federal law called Individuals with Disabilities Education Act (IDEA, for short).¹⁶ Because regional centers receive federal funds for these services, most eligible children get their Early Start services from their regional center.

Instead of an IPP, children under three have an Individual Family Service Plan (IFSP).¹⁷ Children who receive Part C early intervention services can also get Lanterman Act services if they qualify under the Lanterman Act eligibility criteria.

¹⁵ §§ 4685(c)(2); 4648(a)(2) and (10).

¹⁶ 20 U.S.C. §§ 1431 *et seq.*

¹⁷ Some regional centers call their IPPs for people of all ages Individual Family Service Plans.

When they turn three, eligible children start to get services from the school district and the regional center. The regional center must make a plan for the child's transition to the school district, and coordinate the child's services until the transition is complete.

If you have a child under three, please read Chapter 12 of publication 5052.01, *Special Education Rights and Responsibilities*, for information on Part C services. You can get it from Disability Rights California or OCRA.

8. How does the regional center provide the services I need to live with my family?

First, tell your regional center service coordinator about what you and your family need and the challenges you are facing.

Your service coordinator has to tell you and your family about the supports you can get to help you:

- live independently,
- participate in your community, and
- live like people without disabilities, as much as possible.

Your service coordinator should also tell you about the supports your family can get to help them care for you and meet their other responsibilities.

With this information, you, your family, and the regional center can develop an IPP that is right for you. Your IPP should say:

- when your services will start and end,
- who will provide the services, and
- how you will get the services.¹⁸

For more information on the IPP process, see Chapter 4.

After you sign your IPP, the regional center must make sure you get all the services listed in your IPP.¹⁹ It must also make sure there are no "gaps" in your services.²⁰ If you need specialized services, the regional center can pay

¹⁸ § 4646.5(a)(4).

¹⁹ §§ 4646(d); 4647; 4648.

²⁰ §§ 4501; 4648(g).

outside providers (called “vendors”). They may pay the vendor directly or give you vouchers to pay the vendors through a Financial Management Services company. See Chapter 8, question 46.²¹

But before paying for these specialized services, the regional center must use “generic services” to meet the family’s needs.²² See Question 16 below.

9. What does the requirement to be “flexible and creative in meeting individual and family needs” mean?

It means that the regional center:

- does not have to do things in a certain way.
- does not have to do something the same way it was done in the past, or the same way other regional centers do it.
- can create new and different ways to provide services.
- must think of innovative ways to meet your needs.²³ It can work with you and your family to find a solution that works for you.

For example: If the regional center cannot find a vendor to provide your services and you find someone to meet your needs, the regional center can be flexible and hire the person you found. This solves your problem, even though it is not the way the regional center usually works. Keep in mind that if the regional center can meet your needs with a vendor it already has, you probably cannot get a specific person or new service system instead.

10. Will the regional center pay for experimental treatments?

No. Starting July 28, 2009, regional centers cannot purchase experimental treatments, therapeutic services or devices that have not been clinically determined or scientifically proven to be effective or safe or where risks and complications are unknown. Experimental treatments or therapeutic services include experimental medical or nutritional therapy when the use of the product for that purpose is not a general physician practice.

11. Do I have to use the least costly provider?

²¹ §§ 4648(a)(3-5) and (g).

²² § 4659

²³ §§ 4651(a), 4685(c)(2); 4648(a)(2) and (e)(3).

Yes. The Lanterman Act currently requires the IPP (Individual Program Plan) team to consider several factors when selecting a service provider including the provider's ability to deliver quality services and meet the IPP objectives and the cost of providing services or supports of comparable quality by different providers. The 2009 changes to the Lanterman Act include a requirement that the regional center purchase services from the least costly available provider of comparable service.

The regional center, consumer and, where appropriate, the parents or legal representative will review your IPP to determine if you are receiving services from the least costly provider available. In making this decision, the team must consider if:

- The service provider can meet all or part of your IPP;
- The service provider can meet your specific needs and, where appropriate, the needs of your family as set forth in your IPP;
- The services or supports are comparable to your current services or supports;
- The services are as integrated and no more restrictive than your current services.

You cannot be required to use the least costly provider if the services are more restrictive or less integrated. To determine the least costly provider, the regional center, consumer, and where appropriate, the parent or legal representative must consider:

- If the program is eligible for federal funding;
- The cost of transporting you to and from the program.

If your regional center wants to change your service to the least costly provider, it must either hold an IPP meeting and reach agreement with you about the change or give you a written notice of the proposed change.²⁴

²⁴ Usually, decisions about the services you need must be decided by an IPP team. Welfare & Institutions Code Section 4646.4(a)-(c). However, the law says if a regional center wants to reduce, end or change a service in your IPP without your consent, it has to give you a 30 day notice first. Welfare & Institutions Code Section 4710. See chapter 12 of this manual for more information on disagreements with regional centers.

12. Will I get all my IPP services on holidays?

No. The 2009 changes to the Lanterman Act²⁵ required the implementation of a 14-day uniform holiday schedule for:

- work activity programs,
- activity centers,
- adult development centers,
- behavior management programs,
- social recreation programs,
- adaptive skills trainers,
- infant development programs,
- program support groups (day service),
- socialization training programs,
- client/parent support behavior intervention training programs,
- community integration training programs,
- community activities support services, or creative arts programs, and
- transportation services to the programs listed above.

This means that virtually all types of day programs will not receive funding from the regional center on the specified days, and thus you will most likely not receive these services on those days. This also means that the regional center will not provide transportation to these programs on the specified days.

The statute originally required closure on the days between Christmas and New Year and 10 other days including most generally recognized court holidays. However, DDS has the authority to adjust the holiday schedule. For a current listing of the days covered by this section check the DDS website.²⁶

13. Can the regional center limit the amount of services I receive?

²⁵ § 4692

²⁶You can go to www.dds.ca.gov and search for “holidays.”

No. Generally, there is no maximum level of service²⁷. The Lanterman Act says that regional centers must provide individualized services, and every individual has different needs. It is against the law for a regional center to set a minimum or maximum amount of services. However, in 2009, respite services were limited to 90 hours per quarter unless you meet an exemption. See Questions 23 and 24, below.

Regional centers often use “purchase of service” or “POS” policies to decide the amount of services you can get. These are guidelines that regional center service coordinators use to see how much of a service people usually get. For example, many POS policies say that a family with one developmentally disabled person can get up to 12 hours of respite care per month. But the regional center **cannot** use these policies to decide the actual amount of services you get. This is because the Lanterman Act says services must be tailored to the needs of each individual.²⁸ Every regional center POS policy must have a clause that says that there are exceptions to the policy’s general service amounts. At your IPP meeting, your regional center coordinator can follow the regional center’s POS and suggest that your family get 12 hours of respite services per month. But, your IPP team **must** take your family’s circumstances and needs into account before they decide how many hours of respite services you get.

Ask for a copy of your regional center’s POS policies, including the exceptions. Then you can see if your coordinator is using these policies to decide the services you get. If you think the regional center is denying you the amount of services or supports you need because of its POS policy, tell your service coordinator that you want an exception. Ask to have a meeting with someone who can decide to make an exception.

If you still do not get what you need, you can ask for a fair hearing. At the hearing, you can argue that the regional center violated the Lanterman Act by relying on its POS policy instead of taking your individual needs into account.

14. Do parents have to pay for some services for children?

²⁷ See question 22 below for information regarding the limit on respite hours.

²⁸ §§ 4502; 4646; and 4648.

Yes, in some situations, the family must pay for part of some services in the IPP, including:

- **Transportation.**

- For a minor child living with his or her family, the regional center will pay for transportation only when the family cannot provide transportation. If the family needs the regional center to pay for transportation, the family must provide written information, such as a brief letter, to the regional center explaining why.²⁹

Effective July 1, 2011, if you are receiving transportation services from the regional center, and then a transportation access plan shall be developed when:

1. The planning team has determined that your community integration and participation could be safe and enhanced through the use of public transportation services; and,
2. The planning team has determined that such generic transportation services are available and accessible.

The transportation access plan must be determined to be appropriate by the planning team, and shall be developed by the IPP team to maximize your independence and community integration and participation. The transportation access plan shall identify the services and supports necessary to assist you in accessing public transportation. Such services and supports may include, but are not limited to, mobility training services and the use of transportation aides.

- **Out-of-Home Care for Children.**

- If your child is under 18 and gets 24-hour care outside your home, you may have to pay for some of that care. You will not have to pay more than what it would cost to care for a non-disabled child at home.³⁰
- How much you pay depends on your ability to pay. They will take into consideration other expenses you have, like medical bills and transportation to visit your child.³¹

²⁹ § 4648.35

³⁰ § 4782.

- **Day Care.**

- The Lanterman Act expects parents to pay for day care in the same amount they would pay for a child without disabilities.³² The regional center pays for additional costs. If the family shows that it cannot pay, and needs help to take care of the child at home, the regional center can pay the entire cost of day care.³³

- **Diapers. (See Question 17.)**

- **Annual Family Program Fee.**

- Your family has to pay an annual fee if:
 - Your family income is more than four times the federal poverty level³⁴,
 - You are under 18 years of age,
 - You live with your parents,
 - You are eligible for services under the Lanterman Act or Early Intervention Services Act and receive services beyond needs assessment, service coordination, or those services subject to the Family Cost Participation Program, and
 - You are not on Medi-Cal, including the Medi-Cal HCBS DD Waiver.

³¹ § 4784. Also, see Cal. Code Regs., tit. 17 §§ 50201-50241. Disability Rights California believes parental fees must not be charged if the child is a Medi-Cal recipient and is living in a Medi-Cal funded placement, i.e., a nursing facility, an intermediate care facility for people with developmental disabilities, a developmental center, or a community care facility funded under the HCBS Waiver. State and federal Medicaid laws say that the Medicaid payment (Medi-Cal in California) must be considered payment in full. Welf. & Inst. Code 14019.3(d); 42 C.F.R. §447.15. If the child is in a residential placement for educational purposes, the parents would not have to pay. Federal special education law says that “[i]f placement in a public or private residential program is necessary to provide special education and related services to a child with disabilities, the program, including non-medical care and room and board, must be at no cost to the parents of the child.” 34 C.F.R. §300.302.

³² § 4659.

³³ § 4685(c)(6).

³⁴ § 4785(b)

- For more information on the Annual Family Program Fee, see Chapter 1, questions 23 and 33-38.
- **Services under the Family Cost Participation Program.**³⁵
 - Your family has to pay a co-payment for respite, day care, and camping services in your IPP if:³⁶
 - Your family income is more than four times federal poverty level,³⁷ You are under 18 years of age, and
 - You are not on Medi-Cal, including the Medi-Cal HCBS DD Waiver.
 - For more information on the Family Cost Participation Program and the DD Waiver, see Chapter 1 and Supplement D.

Other than these services, the regional center cannot ask you or your family to pay for services in your IPP.

15. How can I help the regional center respect my family's culture?

The law says that the regional center must respect your culture.³⁸ You should get services in ways that are consistent with your cultural values and customs. You should not have to go against your customs to get services.

If you want the regional center to respect your culture, you have to tell them about your cultural values and customs. Be specific so the regional center can understand your culture and what aspects of your culture are important to you.

For example, just because you tell the regional center that you belong to the Chumash Nation does not mean that it knows how to develop services that respect your culture. You may need to explain what part of your culture and language is important to you and your family. This way, you teach the regional center about your culture and give your service coordinator

³⁵ § 4783.

³⁶ § 4783. This parental fee program began on January 1, 2005.

³⁷ In 2006, 400% of the federal poverty level for a family of four was \$6668 a month. The regional center looks at your adjusted gross income (AGI) for the previous year. AGI is your total income after all allowable deductions.

³⁸ §§ 4685(b)(4); 4502.1; 4646.5(a)(1).

information that will help them consider your background. Bring this up at your IPP meeting. Ask for your specific cultural preferences to be included in your IPP.

16. Can I still get regional center services if I do not speak English?

Yes. Regional centers must respect your language needs. Good communication is essential. If you do not speak or understand English, or if you are more comfortable speaking a different language, tell the regional center at your first intake meeting.

If you need an interpreter, tell the regional center as soon as possible. You can have an interpreter at every meeting, including your intake meeting and phone calls. You can also bring a friend or family member who speaks English to help you. But, the regional center cannot make you bring a friend so that they do not have to hire an interpreter. If you need an interpreter to appeal a regional center decision, the regional center must hire and pay for the interpreter.³⁹ For a sample letter to ask for an interpreter, see Supplement T.

You also have the right to have your IPP (and other documents) translated.⁴⁰ If the regional center will not translate documents or give you an interpreter, call Disability Rights California or OCRA.

17. In our culture it is important not to argue. Should we appeal if we do not get all the services we need?

Yes. It is your right to appeal a regional center decision that denies you a service you need. If the regional center disagrees that you need a service, it doesn't mean they are trying to hurt you. If you appeal, it doesn't mean that you are asking for more than you need. It just means that you do not agree on what you need.

The U.S. legal system is adversarial. This means that each side argues their case aggressively. Don't take this personally. For example, in an administrative hearing, the administrative law judge knows that the regional center will argue its case strongly without worrying if you are making your

³⁹ §§ 4710.6(a)(5); 4710.8(c).

⁴⁰ Government Code §§ 7290 *et seq*; §§ 11435.05, 11435.15, 11435.25(b); Welf. & Inst. Code §§ 4502.1, 4646, 4646.5(a)(1), 4701 *et seq*; Cal. Code Regs., tit. 22, §§ 98210(a), (c), (d), 98211(c).

case or not. The judge expects you to argue your case the same way. This way, both sides get to argue their case fully. And, the judge can see the facts clearly.

Don't worry. Just tell the truth when you present your case. The judge will look at the facts and the Lanterman Act and decide the case. Even if you lose your appeal, the regional center cannot retaliate, punish you, or take away your services because you appealed.

For more about appeals, see Chapter 12.

18. What are natural supports?

Natural supports are people or things already in your life that can help you meet your IPP goals.⁴¹ The most common natural supports are parents, family, or friends who can help you. The law says that you should use your natural supports before the regional center pays for services.

If the regional center finds that you have natural supports, make sure that these natural supports are actually available to you. For example, sometimes your parents want to help you, but they work all day. They cannot help you at night because they are tired, or need time to do other things. In this case, your parents cannot be your natural support.

In another example, you have a good friend who likes to help you whenever she can, but she cannot help you consistently because she has other responsibilities. Your friend is not a natural support because you cannot count on her to be available all the time. You may need to prove to the regional center that someone is not a natural support. Your friend can write a letter or go to an IPP meeting (in person or by phone) to explain why she cannot be a natural support.

If you have natural supports, you can tell the regional center who they are and list them in your IPP. Natural supports are a great way to combine your personal life and your regional center services.

19. What are generic services?

⁴¹ § 4512(e).

Generic services are services you can get from another agency that serves the general public.⁴² The law says you must use generic services before the regional center pays for similar services.⁴³ If you can find generic services to meet your IPP goals, you should use them.

If you or your family are eligible for Medi-Cal, Medicare, the Civilian health and Medical Program for Uniform services (CHAMPUS – otherwise known as TRICARE), In-Home Support Services (IHSS), California Children’s Services (CCS), private insurance, or a health care service plan and you or your family choose not to apply for these services, then the regional center cannot purchase services that these agencies would provide for you.⁴⁴

If you or your family does not meet the criteria for the generic services above, then the regional center can continue to purchase these types of services for you.

A regional center can only buy medical or dental services for you if you are over age 3 and:

- You or your family show the regional center that Medi-Cal, private insurance, or a health care service plan has denied the medical or dental service; and

- The regional center decides that an appeal would not have merit.⁴⁵

The regional center may pay for medical or dental services:

- While you or your family are trying to get medical or dental service from another agency or private insurance and you have not yet been given a denial;

- While you or your family are waiting for a final administrative decision and you already provided the regional center with information that you are appealing; or

- Until Medi-Cal, private insurance or a health care service plan begins to provide the services.⁴⁶

⁴² § 4644(b).

⁴³ § 4648(a)(8) and § 4659.

⁴⁴ § 4659(c).

⁴⁵ § 4659(d).

At your IPP meeting, ask the regional center to help you advocate for generic services. That way, you will not be the only one responsible for getting them. If you ask them, the regional center must help you get generic services.⁴⁷ If you have trouble getting the services, ask the regional center to represent you in an administrative hearing.⁴⁸ For more about how to get the regional center to advocate for you, see Chapter 4, Question 47.

20. How will my services be effected by the 2009 cuts to Medi-Cal?

For regional center consumers who are over 21, Medi-Cal will no longer cover certain services. Welfare and Institutions Code section 14131.10 states that Medi-Cal will no longer pay for the following benefits and services for most adults (there are some exceptions - see below):

- Dental services
- Speech therapy services
- Podiatric services
- Audiology services
- Chiropractic services
- Acupuncture services
- Optometric and optician services (ophthalmology [doctor services for the eyes] will continue to be covered)
- Psychology services (psychiatry services, and all services through county mental health programs will continued to be covered)
- Incontinence creams and washes.

However, there are some exceptions to this new law.

The above Medi-Cal benefits and services will NOT change for people who are:

- Under the age of 21; or

⁴⁶ § 4659(d).

⁴⁷ § 4659(d)(2).

⁴⁸ 4648(b).

- Living in a skilled nursing facility (Level A or B; this includes subacute care facilities); or
- Pregnant⁴⁹, or
- Receiving benefits through the California Children's Services program; or
- Receiving benefits through a Program of All-Inclusive Care for the Elderly.

If you do not fall within the exceptions above, you can still receive some or all of the benefits that have been cut, including certain dental services, if you are:

- Receiving the services through the Genetically Handicapped Persons Program; or
- Receiving the benefits through the county mental health program; or
- Receiving the benefits through the Medicare Part B program; or
- Receiving the services directly from a physician.

You should contact your physician or dentist if you have any questions about these changes.

However, even if you do not meet any of the exceptions you may still be able to get certain services:

- If an emergency condition occurs and the benefit is required to treat the emergency condition.
- Some medical and surgical services provided by a dentist will continue to be covered. Check with your dentist for more information.
- Some of these benefits and services may be provided in hospital outpatient clinics, Federally Qualified Health Centers, Rural Health Clinics, Indian Health Services, adult day health care centers, or through home health agencies. Check with your primary health care provider for a referral.

⁴⁹ If you are pregnant, you can continue to receive pregnancy-related benefits and services. You can also receive other benefits and services listed above to treat conditions that, if left untreated, might cause difficulties for the pregnancy. This includes dental exams, cleanings, and gum treatment. Dental and other benefits and services may also be available up to 60 days after the baby is born.

- Some of these benefits and services may be continued if you are currently receiving them or if you move from an exempt group, such as under 21 years of age, to a non-exempt group, such as turning 21 years of age. Check with your primary health care provider for more information.
- Your county health department may be able to provide you some of the benefits and services no longer covered by Medi-Cal.

If you find that you are no longer entitled to one of the services listed above and you do not meet the exceptions, your regional center may have to fund the service under its gap funding responsibilities.⁵⁰ (See Chapter 1, Question 46). If you are not sure if the regional center must fund the services, you can contact Disability Rights California or the Office of Clients' Rights Advocacy in your area.

21. Will the regional center pay for diapers?

They will pay for diapers for people with developmental disabilities who are over three years old. (At three, someone without disabilities usually stops using diapers.)

Note: If you cannot afford to pay for diapers, the regional center may pay for diapers for children under three.⁵¹

22. What are “respite” services?

Respite services are services that hire someone to be with you so your family can have a break, or time to take care of other things.

Respite services are designed to keep you safe while your family members have a break from directly supporting you.⁵² When a respite worker cares for you, your family can leave the house, spend time with family and friends, or take a nap. They do not have to leave the house, but they should take a break.

Family members who live with regional center consumers may be eligible for respite services.⁵³ A “family member” is someone who lives with a developmentally disabled person and is responsible for their care, 24 hours a

⁵⁰ § 4648(g)

⁵¹ § 4685(c)(7).

⁵² § 4690.2.

⁵³ § 4690.2(a) and Cal. Code Regs., tit. 17, § 56782(a)(1).

day. Licensed or certified residential care facilities or foster family homes that get money from a public agency or regional center are not eligible for respite services.⁵⁴ However, relative foster parents are exempted from this general rule. This means that non-relative foster parents cannot get respite services but relative foster parents can.⁵⁵

23. How much respite can I get?

Beginning in July 2009, unless you qualify for an exemption, you can only get a maximum of 90 hours of in-home respite per quarter (or three month period) and 21 days of out-of-home respite per year⁵⁶. Respite hours will only be awarded when you require more care and supervision than a person of the same age without a developmental disability.

A regional center may make an exemption (exception) to the new respite criteria as follows:

1. The intensity of your care and supervision needs are such that additional respite is necessary to keep you living at home; or
2. There is an extraordinary event that impacts the family member's ability to meet your care and supervision needs.⁵⁷

Regional centers cannot purchase day care services to replace respite. Day care services are regular care provided in the parent's home while the parent works or goes to school.

Regional centers often try to limit respite services because it is hard for them to know how families use that time. But, family members need a break from constant care. We believe respite is the most important service for keeping families together and making sure a consumer is well taken care of. Respite offers caregivers the relief they need to ensure that the consumer can stay in the home. This is better for the consumer. And, it saves the state money because caring for a consumer outside the home is much more expensive than respite care.

⁵⁴ Cal. Code Regs., tit. 17, §54302(a)(29).

⁵⁵ § 4686.5(a)(3)(B)(iii)

⁵⁶ As part of the 2009 changes to the Lanterman Act, in-home respite was limited to 90 hours per quarter and out-of-home respite was limited to 21 days per year. (see W&I Code § 4686.5(a))

⁵⁷ § 4686.5(a)

24. What if I need more respite hours?

If you need more hours than the regional center offers, you have to explain why. Write your weekly schedule and bring it to an IPP meeting. Include your activities, the time you spend caring for the consumer, and the times you need respite and why.

You can ask for respite for errands, activities with your other children, church, or free time. Make a list of the behaviors or medical needs (and their frequency) that affect the amount of respite you need. Read publication 5286.01 to help you prepare for the IPP meeting. You can get it from Disability Rights California or OCRA.

25. What can we do if the regional center denied our request for more respite?

If the regional center will not give you the hours you need, you can appeal. Use the Disability Rights California respite hearing packet (publication 5286.01) to help you prepare. You must show the hearing officer why you need more respite.

Once you file for an appeal, start preparing the evidence that shows that your family needs more respite. You need proof of:

- the kind of care you need,
- how often someone must be with you, and
- what a typical week of care looks like.

Get letters or declarations from the people who take care of you. The letters should talk about the kind of care you need, and why your family needs more respite. They should also explain how you meet the exemptions. In other words, they should: 1) address how the intensity of your care and supervision needs are such that additional respite is necessary to keep you living at home; or 2) address how an extraordinary event has impacted the family member's ability to meet your care and supervision needs.⁵⁸ This hearing is your family's chance to explain their needs clearly.

Instead of writing letters or declarations, the people who care for you can go to your hearing and testify. This is not required. But, sometimes personal

⁵⁸ § 4686.5(a)

testimony is better than written documents because the regional center and judge can ask questions to understand why they need more respite.

Your family does not have to do specific things when you get respite care. It is fine for them to say they just need a break. They have to prove that they need the amount of breaks requested to be able to continue caring for you.

26. Is respite free?

Yes. But, if you are under 18 and do NOT get full-scope Medi-Cal, your parents may have to pay for some respite costs as part of the Family Cost Participation Program. For more on how to calculate Family Cost Participation, see Chapter 1, Questions 23-32.

27. Can the regional center ask me to trade my respite hours for other services?

No. Some regional centers ask the consumer to “trade” respite hours for other services, like horseback riding or socialization groups. This limits the number of services your family receives. Disability Rights California believes that this is illegal.

Respite hours give family members a break. The consumer’s need for a socialization program is unrelated to that. The regional center must consider each need independently and individually.

28. Can I choose my own respite worker?

Yes. Regional centers have “vendors” who can hire respite workers. Family members can become a vendor so they can hire a respite worker. To do this, you must get a “voucher” from the regional center. Then you can hire someone and bill the regional center. (Family members cannot provide the respite themselves.) If you hire a respite worker, you must train, monitor, and pay them through a Financial Management Service provider. See Chapter 4, Question 46.

Sometimes, a regional center vendor will hire the respite worker you choose. This way you get respite services from someone you are comfortable with, and the vendor pays the worker and bills the regional center. Many regional centers offer this option, called Employer of Record (EOR) respite. The vendor becomes the employer of your respite worker. You still choose, train, and supervise your respite worker. The vendor hires them and pays their

salary and benefits. The respite worker must complete CPR/First Aid training, certification, and fingerprinting. If you are a vendor, some regional centers now require you to switch to EOR respite. But, they have to have an exceptions policy. To learn more about your options, ask your regional center service coordinator.

29. What are my responsibilities as a family member vendor?

Family member vendors must:

- Make sure that any respite worker they hire is over 18.⁵⁹
- Make sure that any respite worker they hire has the skills, training, or education they need to provide respite. They must also know the consumer's routines and needs and be trained in any special support necessary.⁶⁰
- Complete the Home and Community-Based Services Provider Agreement.⁶¹
- Use the new Respite Services Billing Form DS 1811 to submit requests for reimbursement.⁶² The family member vendor and the respite worker must sign the form.
- Keep records, including:
 - (1) dates and times of respite services, start and end times of the respite,
 - (2) address where the service was provided, and
 - (3) date of birth, social security number,⁶³ address and phone number of the respite worker.⁶⁴ This information is also on billing Form DS 1811.

⁵⁹ Cal. Code Regs., tit. 17, § 54355(g)(4)(C)(1)(a).

⁶⁰ Cal. Code Regs., tit. 17, § 54355(g)(4)(C)(1)(a) & (b).

⁶¹ Cal. Code Regs., tit. 17, § 54310(h).

⁶² Cal. Code Regs., tit. 17, § 54355(b)(4).

⁶³ If a worker does not have a social security number, the vendor can accept a copy of any document that the federal government accepts to prove identity and employment eligibility. The family member vendor must compare the copy to the original. And the worker must declare under penalty of perjury that the copy is true and correct.

⁶⁴ Cal. Code Regs., tit. 17, § 50604(d)(3)(D)&(E).

- Keep records of respite services for five years.⁶⁵ The regional center can audit family member vendors. If the vendors do not have the required records, they may have to pay the regional center back.

30. If I have severe medical or behavioral needs, will my respite worker have the special skills needed to care for me?

Regional centers must train and advise respite workers so they can care for you appropriately. If a worker cannot care for you because of your disability, the regional center must provide a worker with more training and skills, such as a behaviorist or nurse.

In 2009, the law changed to expand the scope of duties for respite workers. The new law increases the number of incidental medical services that an in-home respite worker can provide. Current law allows an in-home respite worker who is not a licensed health care professional to provide gastrostomy feeding and care for consumers who are in a stable condition. Current law also requires that the respite worker be trained by a medical professional.

The new services that may be provided by an in-home respite worker include:

- Colostomy and ileostomy: changing bags and cleaning stoma
- Urinary catheter: emptying & changing bags and care of catheter site
- Gastrostomy: feeding, hydration, cleaning stoma, and adding medication per physician's or nurse practitioner's orders.

In order to provide these services, respite workers must:

- Be employed by an agency that is vendored by a regional center to provide in-home respite services;
- Receive training from a licensed health care professional;
- Provide proof of completion of a first aid course and a cardiopulmonary resuscitation course within the preceding year.

The new law continues to require the consumer's treating physician to tell the regional center that the consumer's condition is stable. The respite agency

⁶⁵ Cal. Code Regs., tit. 17, § 54355(b)(3).

has duties under the new law and should refer directly to the legislation to determine those duties.⁶⁶

The regional center decides how many hours of respite you need and the level of care you need. You may have to have an assessment. For example, you can have a nursing assessment to decide if the person who cares for you needs nursing skills. You can also have an assessment to see if you need a respite worker who is specially trained in behavior intervention.

31. Can my family get someone to help them take care of me?

Yes. Your family can get someone to help when they are caring for you. But, it is not considered respite if they are not getting a break. If your family gets extra support to care for you at home, this will not reduce the hours of respite you can get.

You need to prove that you need the extra services, and how much you need. The regional center cannot deny you extra support just because it does not normally offer it. For example, if you need help to take a bath and the person who usually helps you hurts their back, your IPP can include someone to help bathe you.

32. Can the regional center say I cannot get more respite until I get more IHSS hours from the county?

The 2009 amendments to the Lanterman Act changed your ability to receive some kinds of services from your regional center in the following way:

- a. Unless you meet an exemption, the regional center cannot pay for services that are available through the county's IHSS program when you meet the criteria to receive IHSS but you decline to apply for it;
- b. The regional center can pay for supportive services between the time you apply for IHSS and the time it is approved. However, the rate that the regional center pays for those services cannot be greater than the IHSS hourly rate for the county you live in.
- c. Regional centers are required to use generic services to meet your needs before the regional center purchases services. IHSS is a generic service and

⁶⁶ § 4686.

therefore, the regional center cannot purchase supported living services to replace IHSS services.

Exemption The regional center executive director may make an exception to the rule and pay for services even if you decline to apply for IHSS, if there is an “extraordinary circumstance” that warrants making an exception and it is documented in your Individual Program Plan (IPP).⁶⁷

But, the regional center cannot count your IHSS hours as respite. The amount of respite you get does not depend on IHSS, because they are different services.⁶⁸ IHSS does not count as respite care. But you should use all the In-Home Supportive Services (IHSS) you can get.

IHSS: The county pays someone to care for your personal care needs, like grooming, bathing, and cooking.⁶⁹ IHSS workers only do what is listed on the IHSS worksheet. They do *not* care for all of your needs. You must apply for IHSS services and meet certain requirements to be eligible. (See *Question 27 below.*)

Respite Care: The regional center pays for respite care. Respite gives your care provider a break. Your provider can leave you while the respite workers care for you. And, respite workers must take care of *all* of your needs.

Since IHSS and respite are different, you should not have to use IHSS before getting more respite care. Sometimes the respite worker and IHSS worker do the same things. But, you can only get up to nine hours of IHSS a day (not everyone qualifies for that much). You may have to use IHSS and respite care at different times. You should be able to get the respite you need *and* the IHSS hours you are eligible for.⁷⁰

If your regional center will not give you respite until you get IHSS, call Disability Rights California or OCRA for help.

⁶⁷ § 4689.05.

⁶⁸ § 4648(b)(5).

⁶⁹ §§ 12300 *et seq.*

⁷⁰ Regional center services cannot be counted by the IHSS program as an alternate resource. See DSS All County Letter No. 98-53.

33. Who can get IHSS services?

IHSS is for elderly, disabled, or blind Californians who live at home or are waiting to live at home. You have to meet income and resource requirements. If you get SSI (Supplemental Security Income) or no-cost Medi-Cal, you are automatically eligible for IHSS.

You can also get IHSS if you are eligible for SSI but do not get cash benefits. If your income does not qualify you for IHSS, you may be eligible if you pay for part of the services. If you have to pay part of the cost of IHSS, call Disability Rights California or OCRA to see if you qualify for free IHSS.

34. How do I get IHSS services?

Fill out an application with the IHSS office at your county social services office. You can also apply over the phone. After you turn in your application, a caseworker will assess your needs. For more information about how to prepare for the IHSS needs assessment, read Disability Rights California's publication 5013.01, *IHSS Fair Hearing and Self-Assessment Packet*. For help getting IHSS, talk to your regional center service coordinator.

35. If I am enrolled in the HCBS waiver, can I get protective supervision and have a family member provide IHSS?

Yes. The Independence Plus Waiver program allows you to be enrolled in the Home and Community Based Services (HCBS) waiver and have your parent or spouse provide services, including protective supervision. You can also get protective supervision under the Personal Care Services Program (PCSP).

For more about the Independence Plus Waiver and other recent changes to IHSS, call Disability Rights California or OCRA.

For more information about the HCBS Waiver, see Chapter 1, Questions 22 and Supplement D.

36. If the county denies my request for more IHSS, do I have to have a county hearing before I can ask the regional center for services?

No. You have to ask the county for more hours before you can ask the regional center for similar services.⁷¹ But if the county says no, you are not required to (but you may if you want to) have an administrative hearing. If you

⁷¹ § 4659.

ask for an administrative hearing, the regional center must help you with the hearing.

At your IPP meeting, ask the regional center to represent you in the IHSS administrative hearing. The regional center must provide advocacy services.⁷² This means it must help you get services from other agencies that can help you.

The regional center has a lot of experience with IHSS hearings. They can help you present your case. For example, you can have a regional center nursing assessment to prove that you need certain IHSS services. Without the regional center, it may be hard to hire a nurse to assess you or testify at your hearing. If the regional center will not help you with a hearing, you can file for a fair hearing against the regional center to force them to help you with the IHSS hearing.

Disability Rights California has information to help you prepare for your IHSS hearing. Call OCRA or Disability Rights California and ask for Publication 5013.01. You can also ask for help with your IHSS hearing.

37. Can the regional center help my family with day care?

Yes, the regional center must help families with extra day care expenses because of their minor child's disability.⁷³ Day care means taking care of a person with disabilities while their family works or goes to school. If you get full-scope Medi-Cal, the regional center should pay for any costs that are above the cost of day care children without disabilities. For example, if day care for your child with disabilities costs more than day care for children without disabilities, the regional center must pay the difference.

If you are an adult, the regional center can refuse to pay for day care in your home unless you can show that you cannot go to a day program and that you are already getting as many IHSS hours as you can get.

If your family cannot pay for day care, the regional center must pay for it. Ask for the number of hours or specific help you need. Include this request in your IPP or IFSP. If the regional center refuses to give you the hours you need, you can appeal.

⁷² § 4512(b).

⁷³ § 4685(c)(6).

See Chapter 12 for more information on appeals.

For more about how to get help with day care from the regional center, call Disability Rights California or OCRA and ask for Publication number 5297.01, *You Can Get Help With Day Care From the Regional Center!*

If you are under 18 and do NOT get full-scope Medi-Cal, your family may have to pay part of the costs of specialized day care as part of the Family Cost Participation Program. For more about how Family Cost Participation is calculated, see Chapter 1, Questions 23-32.

You have a right to not be discriminated against by your day care provider. For more information on this right, see Question 39 below.

38. Can the regional center make my family choose between respite and day care?

No. Respite and day care are two separate services. You can ask for both if your family needs them to care for you at home. Day care takes care of you while your family is at work, school, or in training. Respite gives your family time for other things, like chores, or rest. Your family needs to explain to the regional center why and when they need both day care and respite.

It is hard to tell the difference between day care and respite. In both cases, the regional center must help the family find providers who can care for you fully. But, day care is different because it is only meant to help your family go to work or school or training. Respite gives your family a break from caring for you.

If you need day care, you may still need respite. Your family has the right to rest so they can keep caring for you. Day care will not help your family take a break. Going to work is not respite. Actually, your family members may be more in need of respite if they go from work to caring for you and back to work. You may have to have a hearing to prove that you need both day care and respite, and that they both meet your IPP goals.

39. What if my family wants me to go to an integrated day care program but the program says it can't meet my special needs?

Children should be included in community day care programs whenever possible. The Americans with Disabilities Act (ADA) says that day care providers cannot discriminate against children with disabilities. They must

make “reasonable modifications” (changes) to the program, like additional aids and services, so that children with disabilities can participate. But, the day care provider does not have to make all modifications or offer all special services.

Exception: If the changes or services you need present an “undue hardship” or require a “fundamental change in the program,” the program does not have to provide them.⁷⁴

In that case, you can get the extra help you need from the regional center. For example, if the day care program says your child must have a one-to-one aide, and that would fundamentally change that program, the regional center should pay for the aide. The regional center can also advise and train the day care staff.

Get a letter from the program that explains the support you need, or ask a staff member to go to your IPP meeting. Then your IPP can include your need for support from the regional center.

If you have trouble getting the help you need, call Disability Rights California or OCRA, or call the Child Care Law Center at 415-558-8005.

40. If I don’t qualify for day care assistance from my regional center, can I get help somewhere else?

Yes. There are many day care subsidies that can help pay for day care costs. Ask your local child care resource and referral agency for help.

To find out which agency helps people in your county, go to www.rrnetwork.org or call 1.800.543.7793.

41. If I cannot travel because of my disability, can I get someone to take care of me when my family is on vacation?

Yes. The regional center can find and pay for short term respite care outside your home if your family is not available to take care of you.⁷⁵ This can be because the person who cares for you is sick or needs to travel for business or pleasure. You may stay, temporarily, in a nursing facility, intermediate care facility, group home, or approved family home that meets your needs.

⁷⁴ 42 U.S.C. §§ 12182(b)(2)(A)(ii) and (iii).

⁷⁵ § 4212(b).

42. Does the regional center have to provide the services I need even if I am still in high school?

Yes. The regional center must make sure that you get the services you need to meet your IPP goals, even when you are in school. Schools must provide many services to make sure students with disabilities get a free and appropriate public education. So, many of your services may come from the school district.

But children with developmental disabilities do not normally get all their services from their school. They have needs that are not related to education. Even though the school district provides some of those services at school, the regional center must provide them in the home.

You have the right to ask for regional center services in your home, even if you get special education services from the school district.

Here are examples of regional center services you may need:

- **Socialization Programs**

You may need an after-school program to develop social skills. It can be a segregated program (all of the children have a disability) or an integrated program (some children have disabilities, some do not). These programs help you develop skills necessary to interact in the community. You may learn how to buy stamps at the post office, how to walk through the grocery store, etc. If you need extra help to attend an integrated program, the regional center can pay for the help. *(See Question 39 about integrated day care. The concept is the same.)*

- **Communication Services**

These can be communication devices you use when you are not in school or training for your family or others who can help you use the equipment outside of school.

- **Respite**

See Questions 22-32.

- **Behavioral Supports**

Even if you get behavioral services at school, you may need additional services at home. Your school services may be able to address your

behavioral needs in a structured classroom. When you are home, you may need behavioral help to deal with the less rigid structure of a family.

The regional center should actively supplement the services you need at home when you are a student. Make sure to ask for these services in your IPP.

Effective July 1, 2011, the regional centers cannot pay for the following services:

1. Day programs,
2. Vocational education,
3. Work services,
4. Independent living programs, or
5. Mobility training and related transportation services

for people 18-22 years old who are eligible for special education and related services unless exemptions are met.

All of your services should be determined in the IPP process. This is especially important for you during the transition out of school.

When the law changed, it created three groups of people. Each of these groups is entitled to different services.⁷⁶ See Chapter 8 questions 65-68 for more information.

43. What happens after I leave high school?

The regional center must work with you and your family to ensure a smooth transition out of the public school system. You need to decide what to do next. For people 18-22 years old who are eligible for special education and related services, the regional centers cannot pay for day programs, vocational education, work services, independent living programs, or mobility training and related transportation services unless exemptions are met.

⁷⁶ The changes are part of the Budget Trailer Bill (TBL) AB104. You may find the law at http://www.leginfo.ca.gov/pub/11-12/bill/asm/ab_0101-0150/ab_104_bill_20110630_chaptered.html.

The changes regarding Special Education are found at Welfare and Institutions Code section 4648.55.

See Chapter 8, questions 63 - 65 to learn more about the transition process. See Chapter 8, questions 65-68 for more information about day, vocational, work, independent living, mobility, and transportation programming for people who are 18-22 years old.

See Chapter 7 for adult living arrangements.

44. What behavioral services can I get from the regional center?

Regional centers should pay for behavioral services for behaviors that happen at home or in the community, especially if the service:

- helps your family live in harmony,
- increases your independence or integration into the community, or
- increases your chances of living a normal life.

Many people with disabilities have behavioral problems related to their disability, such as temper tantrums, fighting, aggression, stealing, toileting problems, or hurting themselves. These behaviors can be replaced or reduced with positive behavior intervention.⁷⁷ There are different types of behavior intervention. These include parent training, direct intervention in the home, community, or clinic setting. Every type of behavior intervention must use positive, non-aversive interventions.⁷⁸

You must have an assessment before your in-home behavioral program starts.⁷⁹ This assessment looks at your level of functioning, problem behaviors, how often they occur, and how long they last and what happens to provoke the behaviors or as a result of the behaviors. The report should say the amount of services recommended, how much supervision is needed, what the goals of the services are, and the expected outcome.⁸⁰

Many regional centers require that parents participate in parent training before you get direct intervention services. Parent training can be individual,

⁷⁷ § 4512(b).

⁷⁸ Cal. Code Regs., tit. 17, § 50801(a).

⁷⁹ § 4686

⁸⁰ § 4512(b).

or in a group. The regional center must look at your specific situation to decide if parent training is right for your family.⁸¹

Your family may need a behavioral aide to help them put your behavioral program into practice at home. Some regional centers may tell you they do not offer behavioral aides and offer you more respite. You may need more respite. But, respite is not the same as behavioral intervention. Respite providers do not have the training to implement behavioral programs. The regional center must look at your specific situation to decide if you need an in-home aide. They cannot base their decision on a general policy.

If you have challenging behaviors because of a psychiatric condition, you may be eligible for mental health intervention services. These are called therapeutic behavioral services, or TBS. For information on how to ask for TBS, see Chapter 10, question 8.

45. What behavioral services does the regional center offer to children with autism?⁸²

Regional centers offer Applied Behavior Analysis (ABA) and other services to treat children with autism.

ABA uses methods to analyze behavior and research findings to change socially important behaviors, such as hurting yourself, tantrums, non-compliance, and self-stimulation. You can get ABA services in your home or community.

Other related services include Discrete Trial Training (DTT), Intensive Behavior Treatment, behavior consultation with a parent or caregiver, and Social Skills Training.

Regional centers and schools may have to share the cost of ABA services.⁸³ Some regional centers work with school districts to provide ABA-related

⁸¹ Cal. Code Regs., tit. 17, § 50801(a).

⁸² The following services will only be offered when an individual's need is recognized and agreed upon through the IPP process.

⁸³ Fair hearing decisions that support the regional centers' obligation to fund ABA services include:

J.H. v. SCLARC, OAH Case No. L-2002080100 (2002)

Jessica M. v. SCLARC, OAH Case No. L-2005100075 (2005)

Kevin H. and Ryan H. v. SCLARC, OAH Case No. L-2005070717/L-2005070948 (2005)

services like Intensive Behavior Treatment and Social Skills Training at home and at school.

Some regional centers and school districts work together and make a plan that says what ABA services each agency will provide. This plan is usually called a memorandum of understanding (MOU).

Call Disability Rights California or OCRA if you need help getting ABA services through the regional center or school district.

46. If the regional center decides it will pay for behavioral services, how does it know whether the services were actually received?

The Lanterman Act requires that the parent or legal guardian of a child under 18 who is receiving behavioral services, sign a verification of services form to indicate the receipt of services from a vendor. This form is a standardized DDS form which will then be submitted by the vendor to the regional center for payment of services. The failure to sign the form by a parent or guardian cannot result in a change or termination of behavioral services. However, if you cannot sign the form, you should contact your regional center service coordinator and explain the situation. If the regional center changes or terminates behavioral services, it must either hold an Individual Program Plan (IPP) meeting and reach agreement about the change, or provide a written notice.⁸⁴

47. Can a person who is not a licensed professional provide behavioral intervention services?

Tara R. v. HRC, OAH Case No. L-2000110355 (2001)

Evan Z. v. HRC, OAH Case No. 2000010474 (2000)

Justin C. v. HRC, OAH Case No. L-2003070446 and L-2003090217 (2004)

William A. v. HRC, OAH Case No. L-2005030331 (2005)

Kyle R. v. HRC, OAH Case No. 2000010201 (2000)

Alexandra W. v. HRC, OAH Case No. L2000110023 (2000)

D.N. v. OCRC, OAH Case No. L-2002050190 (2002)

J.G. v. SG/PRC, OAH Case No. L-2003040286 (2003)

⁸⁴ The changes are part of the Budget Trailer Bill (TBL) AB104. You may find the law at http://www.leginfo.ca.gov/pub/11-12/bill/asm/ab_0101-0150/ab_104_bill_20110630_chaptered.html

Changes affecting behavioral services are found in Welfare and Institutions Code section 4686.31.

Yes. Paraprofessionals may provide behavior intervention services. A paraprofessional is a person who is trained to assist a professional in the provision of services, but is not themselves licensed at a professional level. DDS allows a paraprofessional to provide behavior services if the paraprofessional (1) has a High School Diploma or the equivalent, has completed 30 hours of competency-based training designed by a certified behavior analyst, and has six months experience working with persons with developmental disabilities; or if the paraprofessional (2) possesses an Associate's Degree in either a human, social, or educational services discipline, or a degree or certification related to behavior management, from an accredited community college or educational institution, and has six months experience working with persons with developmental disabilities.⁸⁵

The regional center must provide you with a written notice of action before making any changes to your services that you do not agree with including changing your current behavioral services to include the use of a paraprofessional.

48. If my behavior or health gets worse, can my family get help to keep me at home?

Yes. The Lanterman Act says that regional centers must provide emergency and crisis intervention services for you to stay in your home.⁸⁶ You can get crisis intervention services, like mental health services, behavior modification, or nursing support in your family home.⁸⁷

If the services are not successful, the regional center must provide emergency housing in your community. If you must move to another community, the regional center must make every effort to return you to your home with all the supports you need, as soon as possible.⁸⁸ *(For more information, see Chapter 1, Question 12.)*

⁸⁵ § 4686.3 and **California Code of Regulations §54342 and §57332.**

⁸⁶ § 4648(a)(10).

⁸⁷ § 4648(a)(9)(C).

⁸⁸ § 4648(a)(10).

There are several children's crisis homes in California that offer intensive behavioral supports. These two-person homes help children manage their behavior so they can go home. The Regional Resource Development Projects (RRDPs) usually refer children to these homes.

If you have a psychiatric disability and get full-scope Medi-Cal, you can also get Therapeutic Behavioral Services (TBS). TBS are one-to-one services that help you and your family learn new ways to control problem behavior and increase the types of behavior that will allow you to be successful. (*For more information on TBS, see Chapter 10, Question 7.*)

49. Will the regional center pay for in-home nursing care?

Yes. If you need nursing care in your home, the regional center, private health insurance, Medi-Cal, or other programs can pay for it.⁸⁹ People often prefer to get nursing care through the regional center, but you must utilize your generic services as appropriate. Many families use a combination of sources to pay for their nursing care. Most private insurance companies have lifetime limits on services. Nursing care can be very expensive and quickly reach the lifetime limit. If you are eligible for Medi-Cal directly, or through the HCBS DD Waiver, Medi-Cal can provide nursing care in your home. (*See Chapter 1, Question 22 and Supplement D.*)

50. How can we find good health care?

It is not easy to find good health care for a person with a developmental disability. Unfortunately, because of the national health care crisis, there is no easy way to solve this problem. And resources often depend on where you live. It is usually easier to find health care providers in bigger cities than in rural areas.

To find a provider:

- Work closely with your regional center service coordinator. Ask for lists of all medical or dental providers in your area.
- Ask for references from schools, service providers, and other consumers and families.
- Go to meetings about health care.

⁸⁹ § 4659.

- Go to the Department of Developmental Services' website, at www.dds.ca.gov. Look for information on health care and what it calls its "Wellness Initiative." DDS and regional centers have created special programs in some areas for specific health care issues for people with developmental disabilities.
- In the Santa Clara area, Agnews Developmental Center has an out-patient clinic that offers medical care to people in the community.

When you do find a good provider, do your best to develop a positive relationship with that person.

51. Can I get independent living services if I am an adult who is not ready to move out of my parents' house?

Yes. You have the right to any services that help you meet your IPP goals, even if you still live with your parents. Many regional centers do not train adults in independent living skills in their family home. The regional centers think that the other adults you live with will teach you what you need to know. Disability Rights California believes this is not acceptable.

Many people without disabilities choose to live with their parents but still want to cook their own food, buy their own things, and lead their own lives. You have that same right. The regional center must make sure you can live appropriately in the home you chose. So, it must give you the services you need to live as independently as possible in your family home. Make sure that your IPP says that you need independent living skills training, or other specific services you need to be as independent as possible.

For more information on independent living skills training, see Chapter 7, Question 4.

52. Can I get supported living services if I live with my parents or conservator?

No. You cannot get Supported Living Services. But, you can get the services and supports you need to stay in your living situation. These supports can be similar to SLS, if necessary.⁹⁰

⁹⁰ See *J.K. v. Office of Administrative Hearings, et al*, 2004 WL 2713269 (Cal.App. 4th Dist), an unpublished California Court of Appeal decision about SLS. The court said that adult regional

The Lanterman Act says that you must live in your own home and have control over the home to get SLS.⁹¹ DDS regulations say that you are not eligible for SLS if you live with your parent or conservator.⁹² Some regional centers try to deny SLS to people who live with other family members. But Disability Rights California does not agree. For example, if you can show that you have equal control of your home, even if you live with your sister. This means you should be able to get SLS.

The Lanterman Act says that you can get the supports and services you need in order to live where you choose. So, if you need supports and services to help you live with a parent or conservator and participate in your community, ask your IPP team to include those services in your IPP. It does not matter that the services you are asking for are similar to supported living services.

For example, you can ask the regional center for:

- 24 hour a day supports to live in your parents' home, or
- Training to improve your independent living skills, or
- Help to participate in community recreational activities, or
- Supported employment or transportation.

You do not have to move out of your family home to get the services and supports you need. See Supplement P at the end of this chapter.

53. If my child and I both have a developmental disability, can we both get regional center services?

Yes. You have a right to regional center services that help you meet your IPP goals. You also have a right to regional center services that help you parent your child.⁹³ If your child has a developmental disability, your child also has a right to regional center services.

You and your child will have separate IPPs. But, some of the information on your IPPs should be similar. Make sure that your IPPs work in harmony. The

center consumers who live in their family's home cannot receive SLS, but they can receive the services and supports they need.

⁹¹ § 4689(a)(4); Cal. Code Regs., tit. 17, § 58613.

⁹² Cal. Code Regs., tit.17, § 58613(a)(2)(b).

⁹³ § 4687(b).

IPPs do not need to be written at the same time or in the same way. Disability Rights California recommends that you write your IPPs separately. That way, your service coordinator and your child's service coordinator can focus on your needs independently. Bring a copy of your child's IPP to your IPP meeting. This will help you make sure your services work together.

Ask for all the help you need. Remember that you can ask for supports to help you be the best parent possible **and** supports for your other life needs. Being a parent is a very important part of your life, but you have other needs, just like any parent. The regional center must help you parent, but they must also help you maximize your potential as a person.

You can also get help from places like Through the Looking Glass. Through the Looking Glass is a national organization that supports parents with disabilities. They can give you ideas about what you may need. Go to their website at www.lookingglass.org, or call (800) 776-5746.

54. What is the Adoption Assistance Program (AAP)?

AAP is a federal program⁹⁴ implemented by the states⁹⁵ that encourages people to adopt children in foster care, or who are likely to end up in foster care. The program offers financial incentives to the adoptive family.

You have to meet three requirements to be eligible for AAP:

1. The child must be under age 18 (or under age 21 if the child has a mental or physical disability and still needs help).
2. The child is not likely to be adopted without financial help because of factors like age, disability, brothers and sisters that need to stay together, race, ethnicity, or color.
3. The courts must be involved and have determined that the adoption is in the best interest of the child.⁹⁶

International and independent adoptions are not eligible for AAP.

55. How are AAP rates determined?

⁹⁴ Generally see 42 U.S.C. §§ 670 *et seq.* and 45 C.F.R. §§ 1356.40 and 1356.41.

⁹⁵ California has agreed to participate in the federal program, see Welfare & Institutions Code §§ 16115.5 *et seq.* The implementing regulations are at Cal. Code Regs., tit. 22, §§ 35000 *et seq.*

⁹⁶ Welfare & Institutions Code § 16120.

The AAP rates were revised in 2007. Usually, the county's social services department decides the rate. But before July 1, 2007, for children who are eligible for AAP and regional center services (called dual agency children), they use the rates set for community care facilities. These are called Alternative Rate Model (ARM) rates.

The regional center determines the facility level the child would be in if the child were not adopted. The regional center submits this rate to the county. This is the maximum rate the county pays. After July 1, 2007, regional centers will not write rate letters for children who become eligible for benefits.⁹⁷

As of July 1, 2007, dual agency children eligible under the Lanterman Act will get \$2006 per month.⁹⁸ Dual agency children eligible under the California Early Start Intervention Services Act will get \$898 per month.⁹⁹ Children who received more than \$2006 per month prior to July 1, 2007, will continue to get the higher amount.¹⁰⁰ Dual agency children over 3 years old can get a supplement of up to \$1000 per month.¹⁰¹ Contact your local Disability Rights California office for information on how to get this supplement.

56. Does the AAP rate change?

Children are reassessed every two years.¹⁰² The payments could change for children who got or had a pending AAP agreement *before* July 1, 2007.¹⁰³

Children who got their benefits *after* July 1, 2007 will only have a change in benefits if they get the supplement.

⁹⁷ If the family is not satisfied with the ARM rate that the regional center assessed for the child, they can file an appeal with the Office of Administrative Hearings. See *J.R. v. San Diego Regional Center*, OAH Case No. 2003060368, *Canyon C. v Regional Center of Orange County*, OAH Case No. 2002100299, *Scott G. v. North Los Angeles County Regional Center*, OAH Case No. 2004090554, *Natalie P-M. v. San Gabriel Pomona Regional Center*, OAH Case No. 2004060491, and *Joseph F. and Jadili S. v. North Los Angeles County Regional Center*, OAH Case Nos. 2004060495 and 2004060496.

⁹⁸ WIC § 11464(c).

⁹⁹ WIC § 11464(d).

¹⁰⁰ WIC § 16121(c)(2)(B).

¹⁰¹ WIC 11464(b)(2)

¹⁰² Cal. Code Regs., tit. 22, § 35343.

¹⁰³ WIC § 16121(c)(2)(B).

57. If my children get AAP, can they still get regional center services?

Yes. Regional center services are a right under the Lanterman Act.¹⁰⁴

Regional centers try to say that the AAP money should pay for services like respite or behavioral services. But, administrative hearings have repeatedly found that AAP funds are not a generic resource and do not have to be used to pay for regional center services.¹⁰⁵

58. How do AAP benefits affect other government benefits?

CalWORKS AAP payments are not counted as income in the family's CalWORKS' payment.

Food Stamps AAP payments are not counted as income before the adoption is final. This is because the child is considered a boarder. After the adoption is final, the AAP payment is treated as income.

Section 8 You may not be eligible for Section 8 Housing if you get AAP payments. If you already live in Section 8 housing, AAP may cause your rent to go up.

SSA Until the adoption is final, the county keeps the child's SSA benefits and the adoptive family only gets the AAP payment. After the adoption is final, the adoptive parents receive the child's SSA benefits and the SSA benefits may lower the amount of AAP you can get.

SSI AAP is counted as income. The amount of AAP affects your SSI grant. But, SSI does not affect the amount of AAP you can get.

59. How long do AAP benefits last?

¹⁰⁴ WIC § 4684(c)(1).

¹⁰⁵ Cases that found that AAP is not a generic resource include: *L.H. v. Valley Mountain Regional Center*, OAH Case No. 2002080370, *Rebecca K. v. Regional Center of the East Bay*, OAH Case No. 2000030471, *Breanna W. v. San Andreas Regional Center*, OAH Case No. 2000120046, *T.S., C.S., and J.S. v. San Gabriel/Pomona Regional Center*, OAH Case Nos. 2003050412, 2003050413, and 2003050414, and *Jareth S. and Candace S. v. North Los Angeles County Regional Center*, OAH Case Nos. 2000010339 and 2000010340.

In general, AAP benefits last until the child is 18. Children who get regional center services get AAP until they are 21.¹⁰⁶

60. What happens if I move out of California?

The AAP payment will continue at your current assessed rate. The maximum payment will still be governed by California state law. Your move will not affect maximum payment amounts.¹⁰⁷

61. Can children in foster care get special rates of payment if they are regional center clients?

Yes. As of July 1, 2007, dual agency children eligible under the Lanterman Act receiving AFDC-FC benefits have the right to get \$2006 per month. Dual agency children eligible under the California Early Intervention Services Act can get \$898 per month.

62. Are children in foster care eligible for a personal and incidental allowance?

Foster care agencies pay for the following items for children in foster care:

- Clothes,
- School supplies, and
- Personal and incidental needs.

This is part of the payment foster care agencies make each month. Anyone who became a foster child before July 1, 2007 has a right to receive his/her own allowance from this money.¹⁰⁸

On July 1, 2007, this law was changed. And we still do not know what effect it will have. It's best for you to keep records of your personal and incidental costs, and ask DSS to reimburse you. If DSS refuses, ask the regional center to reimburse you. If the regional center refuses, call Disability Rights California or OCRA.

¹⁰⁶ Cal. Code Regs., tit. 22, § 35333(h)(2).

¹⁰⁷ Cal. Code Regs., tit. 22, § 35333(c)(1)(B).

¹⁰⁸ § 4684 and All County Letter No. 98-28.