

This article provides a brief overview of California's Regional Center system and explains why parents are absolutely encouraged to pursue Lanterman Act eligibility status and maintain it.

A Regional Center is a private, nonprofit agency that is contracted by California's Department of Developmental Services (DDS) to coordinate lifelong services for individuals with intellectual and developmental disabilities and their families. There are 21 Regional Centers that serve approximately 450,000 developmentally disabled children and adults in California. Each Regional Center receives funding from the State of California, private donations, and from the federal government.

California's DDS and every Regional Center must adhere to The Lanterman Developmental Disabilities Services Act of 1969, commonly referred to as "The Lanterman Act". This law grants eligible residents with developmental disabilities a legal right to services and supports that allow them to live as independently, productively, and integrated into their communities as possible. This law established an entitlement to care and created the 21 Regional Centers we have today, each charged with providing personalized planning and support to the "consumers" they serve.

Early Start Services

Early Start services are provided to infants and children under age 3 who have developmental delays, disabilities, or are at high risk for having a developmental disability. *By definition, every child age birth to three years with a diagnosis of Prader-Willi syndrome (PWS) is eligible to receive Early Start services.* Early Start services are paid for by the federal government and coordinated by the Regional Center. Services should be tailored to your infant or child's needs with the goal to minimize the effects of the disability. Decisions about supports, services, and goals are made by a team including the parents, Regional Center case coordinator, evaluators, and service providers and documented in the Individualized Family Service Plan (IFSP). Services are usually provided in the family home or in a daycare. The Core Therapies recommended for infants and children with PWS participating in Early Start include:

- **Oral Motor Therapy** to help with feeding issues in infancy and assist with speech articulation as the child ages
- **Speech and Language Therapy** to help with communication skills (Dyspraxia of Speech is common)
- **Occupational Therapy** to help with fine motor skills including finger and hand skills, hand-eye coordination, sensory integration deficits
- **Physical Therapy** to help with strength, movement, balance, and mobility
- **Service Coordination** to help identify endocrinology specialist care for growth hormone treatment, and other specialized support needs

What Happens After Early Start Services End at Age 3

Federally-funded Early Start Services end at age 3 years. At about age 2 – 2½ years, the Regional Center should schedule a Transition Planning Meeting to ensure a seamless shift of supports, evaluations, and services when the child ages out of the Early Start program. This Planning Meeting generally consists of parents, the Regional Center service coordinator, and a representative from the school district, all of whom work together to determine what supports and services are appropriate for the child within the school setting.

Also at about age 2½, but not less than 90 days before the child turns 3, the Regional Center must conduct an assessment of the child to determine whether the child meets Lanterman Act eligibility criteria. If eligibility criteria are met, the child will be eligible to receive supports and services under the Lanterman Act through the Regional Center system in *addition* to the educationally-based supports and services provided by the school district. The assessment and written notice of eligibility must be completed *prior* to the child's 3rd birthday to ensure that eligibility is established well before the child turns age 3.

If your Regional Center determines that your child does qualify for Lanterman Act eligibility, you should be notified in writing. Your case will be transferred from Early Start, and you will be assigned to a new case coordinator who will coordinate a meeting with you and another group of professionals to develop a new document called the Individual Program Plan (IPP) which outlines new goals and a plan of supports and services to meet those goals.

Many Regional Centers misguidedly inform parents that their child has "graduated" out of the Regional Center system, or that Regional Center services end when the child turns three years old and the school district "takes over". While it is true that *Early Start services end at age three* and the school district becomes responsible for providing *services that relate to the child's educational needs*, individuals with PWS may absolutely be made eligible to receive Lanterman Act supports and services.

What is Lanterman Act Eligibility

The Lanterman Act is the law that guarantees California residents with developmental disabilities an entitlement to lifelong services and supports. PWCF strongly encourages families to pursue Lanterman Act Eligibility because it continues to be successfully argued that *individuals diagnosed with PWS by virtue of the disabling condition of their symptoms meet eligibility criteria for The Lanterman Act*. For families whose child is older than 3 years, it is *never* too late to apply for eligibility.

Eligibility is determined through the local Regional Center. To be eligible for Regional Center services under The Lanterman Act, an individual must have a qualifying developmental disability that originated before age 18, is expected to continue indefinitely, and constitutes a "substantial disability".

There are four specified diagnoses listed in The Lanterman Act: Cerebral Palsy, Epilepsy (seizure disorder), Autism, and Intellectual Disability (generally defined as an IQ of 69 or below). Many individuals with PWS will meet the eligibility criteria for Intellectual Disability, some will meet eligibility criteria for Autism, a few will meet the criteria for Epilepsy, and the remainder of individuals with PWS can successfully be argued to meet what is called the "Fifth Category" of eligibility.

The Fifth Category is defined as "disabling conditions found to be closely related to intellectual disability or to require treatment similar to that required for individuals with intellectual disability, but shall not include other handicapping conditions that are solely physical in nature."

The Fifth Category of eligibility covers disabling conditions that are "closely related" to an intellectual disability or require similar treatment. To qualify under the Fifth Category, a person must meet the following criteria:

- **Onset:** The disabling condition must have originated before the individual turned 18 years old.
- **Duration:** It must be expected to continue indefinitely.
- **Functional Impact:** The individual must function in a way that is similar to someone with an intellectual disability or require the same level of treatment.
- **Severity:** It must constitute a "substantial disability" that affects major life activities.

California's criterion of a "substantial disability" is defined as having "significant functional limitations in three or more of the following areas of a major life activity":

1. Self-Care
2. Receptive and expressive language
3. Learning
4. Mobility
5. Self-Direction
6. Capacity for independent living
7. Economic self-sufficiency

What if Lanterman Act Eligibility is Denied?

If your Regional Center determines that your child does *not* meet Lanterman Act eligibility criteria, you should be notified in writing and given the opportunity to appeal the decision. ***PWCF strongly advises families to appeal a Regional Center decision to deny Lanterman Act eligibility. We can help you through the process.***

The Regional Center should include an Appeal Form with their letter of denial. You have ten (10) days from the date you receive the Regional Center's letter to submit your written appeal of the decision. ***PWCF recommends that you write on your Appeal Form that you request "Aid Paid Pending" so that your child may continue to receive their current supports and services uninterrupted throughout the appeal process.*** PWCF highly recommends that you send your Appeal Form "Return Receipt After Mailing" so that you have proof that the Regional Center received your Appeal within the 10-day limit. If you fail to submit your letter of appeal within the 10-day time limit, all of the services your Regional Center has been providing will be terminated.

What if Provisional Eligibility is Granted

If a child age three or four years of age is deemed not eligible for Lanterman Act services, the Regional Center may find them Provisionally Eligible, a new designation as of 2022. Provisional Eligibility may be granted to a child age 3 or 4 who does not have a lifelong permanent developmental disability diagnosis. Provisional Eligibility is a temporary status that ends at age 5 unless the child undergoes reassessment and is reclassified under full Lanterman Act eligibility.

PWS is a permanent lifelong developmental disability diagnosis. ***PWCF strongly encourages families to appeal a decision of only Provisional eligibility. We can help you through the process of pursuing full Lanterman Act eligibility.***

Supports, services and programs *not* provided to Provisionally Eligible consumers include:

- **Medi-Cal HCBS-DD Waiver & Institutional Deeming:** Provisionally eligible children cannot use the Home and Community-Based Services Waiver. This also means they do not qualify for "institutional deeming", which allows families to access full-scope Medi-Cal regardless of household income.

Without a Medi-Cal HCBS Waiver families are not able to receive:

- In-Home Supportive Services (IHSS): In-home personal care and assistance to individuals with disabilities.
 - Personal Care & Respite: Help with daily living activities (bathing, dressing) and temporary relief for caregivers.
 - Home Health Care & Therapies: In-home nursing, medical equipment, and physical, occupational, speech therapy.
 - Wraparound & Behavioral Services: Case management, counseling, and community-based behavioral support.
- **Self-Determination Program (SDP):** Provisionally eligible children do not qualify for this program.

What are the Supports and Services that Regional Centers Can Provide

While each Regional Center is its own independent non-profit, all must follow the rules and regulations of the Lanterman Act and California's Department of Developmental Services. Below is a partial list of services available through a Regional Center:

Adaptive equipment services	Follow-along services	Social skills training
Advocacy assistance or facilitation	Foster family placement	Social recreational services
Assessment	Habilitation	Sociolegal services
Assistance in finding, modifying and maintaining a home	Home location assistance	Special living arrangements
Behavior Modification	Homemaker services	Specialized dental care
Camping services	Identification of circles of support	Speech therapy
Childcare	Infant stimulation programs	Support services for consumers in homes they own or lease
Community integration services	Information and referral services	Supported employment
Community residential placement	Mental health services	Supported living arrangements
Community support facilitation	Occupational therapy	Technical assistance
Counseling for the consumer and/or family	Paid neighbors	Training
Daily living skills training	Paid roommates	Transportation services
Day care	Parent training	Treatment
Development and provision of a 24-hour emergency response system	Peer advocates	Vouchered services
Development of unpaid natural supports	Personal care or assistance	Services and supports that are necessary for families to <i>maintain</i> their child with developmental disabilities at home, when living at home is in the best interest of the child
Diagnosis	Physical therapy	Services and supports needed to maintain and strengthen the family, when one or both parents is developmentally disabled
Diapers	Protection of civil, service & legal rights	Other service and support options which would result in greater self-sufficiency for the consumer and cost-effectiveness to the state
Domiciliary or in-home care	Protective services	
Education	Provision of circles of support	
Emergency and crisis intervention	Recreation	
Emergency relief for personal care attendants	Recruiting, hiring, training personal care attendants	
Evaluation	Respite (co-payment may be required)	
Facilitated circle of support	Respite for personal care attendants	
Facilitation, including outreach & education	Sexuality training	
Financial assistance	Sheltered employment	
	Social services	

Important Resources

- [Directory of Regional Centers](https://www.dds.ca.gov/rc/listings/) <https://www.dds.ca.gov/rc/listings/>
- [Department of Developmental Services \(DDS\)](http://www.dds.ca.gov) www.dds.ca.gov | 916-654-1888
- *A Consumer's Guide to the Lanterman Act* available from the Department of Developmental Services
[English Version](http://www.dds.ca.gov/wp-content/uploads/2021/03/Consumer_Guide_To_The_Lanterman_Act.pdf) www.dds.ca.gov/wp-content/uploads/2021/03/Consumer_Guide_To_The_Lanterman_Act.pdf
[Spanish Version](http://www.dds.ca.gov/wp-content/uploads/2021/03/Consumer_Guide_To_The_Lanterman_Act_Spanish.pdf) http://www.dds.ca.gov/wp-content/uploads/2021/03/Consumer_Guide_To_The_Lanterman_Act_Spanish.pdf
- [Disability Rights Advocates](https://www.disabilityrightsca.org) <https://www.disabilityrightsca.org>
- [Association of Regional Center Agencies](http://www.arcnet.org) www.arcnet.org
- [State Council on Developmental Disabilities](http://www.scdd.ca.gov) www.scdd.ca.gov

PWCF Is Here to Support You

Stay informed of the laws; don't let your child or your family be denied important supports and services that can help you. **You are your child's best advocate, and PWCF is here to help you advocate every step of the way.**

Contact PWCF for more information about Regional Center eligibility, supports, and services and when we may be of support or assistance to you and your family.

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