

This article will provide a brief overview of California's Regional Center system and explain why parents should pursue eligibility status and maintain it.

A Regional Center is a private, nonprofit agency that is contracted by the state of California to provide services to people who have developmental disabilities. Regional centers receive their funding from the state of California and from private donations. There are 21 Regional Centers that serve approximately 220,000 developmentally disabled children and adults in California. The Lanterman Developmental Disabilities Services Act of 1969 is the law that spells out the rules and regulations that all Regional Centers must follow. Governed by their own board of directors, each Regional Center must abide by the Lanterman Act as well as adhere to their specific contract with the California Department of Developmental Services (DDS).

By definition *every child age birth to three years who has received a diagnosis of Prader-Willi syndrome is eligible to receive Early Start early intervention services provided by their Regional Center.* Additionally, it continues to be successfully argued that *all individuals with PWS should be made eligible to receive Regional Center services for the remainder of their lives.*

Shortly before your child turns 3 years old, your Regional Center caseworker will coordinate an assessment of your child in order to make a determination as to whether your child meets the criteria, as established in the Lanterman Act, to be eligible to continue to receive services provided by the state of California through the Regional Center system.

There are four specified diagnoses - Cerebral Palsy, Epilepsy (seizure disorder), Autism, and Mental Retardation - written into the law that are automatically eligible to receive services if they meeting the State's criterion of a "substantial disability" 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

A "Fifth Category" for eligibility includes "disabling conditions found to be closely related to mental retardation or to require treatment similar to that required for individuals with mental retardation, but shall not include other handicapping conditions that are solely physical in nature." Many children with PWS will meet the criteria for Mental Retardation, a few will meet the criteria for Epilepsy, and the remainder of individuals with PWS can successfully be argued to meet the Fifth Category of eligibility. (Many years ago PWCF advocated California legislature to include PWS as an automatic eligible condition, but the then-Governor vetoed the bill. When the "climate" is right, we will once again pursue amendments to the law to include PWS.)

Many Regional Centers mistakenly inform parents that Regional Center eligibility terminates when the child turns three years old because the school district "takes over" or that the child has "graduated" out of the Regional Center system. While it is true that *Early Start* early intervention services end at age three years when the school district takes over responsibility for providing services that relate to the child's *educational* needs, individuals with PWS may absolutely be made eligible to continue to receive Regional Center services.

Prader-Willi California Foundation strongly advises all families to maintain Regional Center eligibility no matter how well your child is currently doing because you never know what services your child or adult with PWS may one day need or want and it is far easier to maintain eligibility than to pursue it later. For families whose child is older than 3 years, it is *never* too late to apply for eligibility.

All families are encouraged to get a copy of the easy-to-read book *Rights Under the Lanterman Act*, written by Protection and Advocacy, Inc., and the Department of Developmental Services publication titled, *A Consumer's Guide to the Lanterman Act*. The links and contact information for these books and organizations are listed at the end of this article. Stay informed of the laws; don't let your child or your family be denied services you're entitled to. You are your child's best advocate!

If your Regional Center determines that your child does qualify for eligibility, you will be notified and your case will be transferred from Early Start and you will be assigned to a new case manager. Your current services should continue uninterrupted *unless* they can be provided by your child's school district.

If your Regional Center determines that your child does *not* qualify for eligibility, you should be notified in writing and given the opportunity to appeal the decision by completing an appeal form that should be included with the letter. You have ten (10) days from the date you receive your Regional Center's letter to submit your written appeal of this decision. You must submit your appeal form with your written request that you receive "Aid Paid Pending" within the ten (10) day time limit so that your appeal is properly served and so that services continue uninterrupted throughout the eligibility appeal process. Be sure to send your appeal letter Return Receipt After Mailing so that you have proof the Regional Center received your appeal. If you fail to submit your letter of appeal within the ten (10) day time limit, all of the services your Regional Center has been providing will be terminated. **Prader-Willi California**

Foundation strongly advises all families to appeal a Regional Center decision to deny eligibility to a child with Prader-Willi syndrome because it can be successfully argued that *all individuals with PWS qualify for Regional Center eligibility under current law.*

The Department of Developmental Services currently contracts with Protection and Advocacy, Inc. to help consumers and family members resolve disputes with their Regional Center. PAI services are offered free of charge, though the agency is often so overwhelmed with work it can be difficult to get assistance. If you have any questions about the services you are receiving or wish to receive, if you have been denied a service or the continuation of a service you believe is of benefit to your child and/or your family, and/or if your child has been denied eligibility, contact your PAI office. If PAI is not able to assist you, or if they can't help in a timely manner, you may wish to contact an attorney who has experience aiding families who have disputes with a Regional Center (and, if you have a school-age child, preferably one who is knowledgeable about the educational legal system as well), or contact the Prader-Willi California Foundation.

If you never utilize the services available through the Regional Center system, terrific! But if you or your child ever do need a service that is provided by the Regional Center, it is far easier to receive a service if you have maintained eligibility than to initiate the eligibility process and try to re-enter the Regional Center system.

Services and Supports Provided by Regional Centers:

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

Resources

- Directory of Regional Centers www.dds.ca.gov/RC/RCList.cfm
- Department of Developmental Services (DDS) www.dds.ca.gov
- *A Consumer's Guide to the Lanterman Act*, available from the Department of Developmental Services
English Version www.dds.ca.gov/ConsumerCorner/docs/LA_Guide.pdf
Spanish Version www.dds.ca.gov/ConsumerCorner/docs/la_guide_SpanishVersion.pdf
Or call 916-654-1888 or write to Department of Developmental Services, Office of Human Rights and Advocacy Services, Attn: Consumer's Guide, 1600 Ninth Street, Room 240, MS 2-15, Sacramento, CA 95814
- *Rights Under the Lanterman Act*, (Book #5063.01), Protection and Advocacy, Inc.
www.disabilityrightsca.org/pubs/506301coverpages.pdf
- Association of Regional Center Agencies www.arcenet.org
- State Council on Developmental Disabilities www.scdd.ca.gov
- Disability Rights Advocates 800-390-7032 www.disabilityrightsca.org/ocra