

The Care Notebook

The following pages were designed to be used in a 3-ring binder called a Care Notebook. The Care Notebook is a tool you can use to organize information about your child's needs. There are many pages that can be filled out to use as a reference about your child's health and treatments. The notebook can then be taken with you to share with doctors, other health care professionals, or school or child care personnel.

- The first page is envisioned as the cover of the notebook with your child's name and picture inserted.
- There are pages labeled as "tabs" which are designed as tabbed notebook dividers.

Uses for the Care Notebook include:

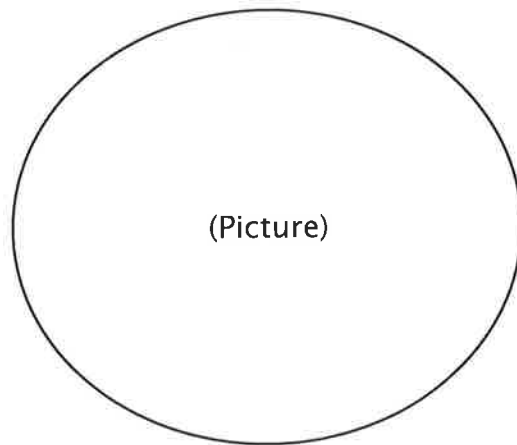
- Tracking changes in your child's medicine or treatments
- Listing phone number for health care providers and community organizations
- Preparing for appointments
- Filing information about your child's health and educational history (IFSP, IEP, IPP, therapy, reports, CCS reports, etc.)
- Sharing new information with your child's primary doctor, public health or school nurse, child care staff, and others caring for your child.

If you have any questions or need additional resources, please contact Comfort Connection Family Resource Center at (714)558-5400.



**Comfort Connection
Family Resource Center**

Care Notebook



(Name)



EMERGENCY TAB

Emergency Information Form for Children With Special Needs

Last name:

 American College of
Emergency Physicians*

American Academy
of Pediatrics



Date form
completed
By Whom

Revised
Revised

Initials
Initials

Name:		Birth date:	Nickname:
Home Address:		Home/Work Phone:	
Parent/Guardian:	Emergency Contact Names & Relationship:		
Signature/Consent*:			
Primary Language:	Phone Number(s):		
Physicians:			
Primary care physician:		Emergency Phone:	
		Fax:	
Current Specialty physician: Specialty:		Emergency Phone:	
		Fax:	
Current Specialty physician: Specialty:		Emergency Phone:	
		Fax:	
Anticipated Primary ED:	Pharmacy:		
Anticipated Tertiary Care Center:			

Diagnoses/Past Procedures/Physical Exam:	
1. _____	Baseline physical findings: _____
_____	_____
2. _____	_____
_____	_____
3. _____	Baseline vital signs: _____
_____	_____
4. _____	_____
_____	_____
Synopsis: _____	_____
_____	Baseline neurological status: _____
_____	_____
_____	_____

Last name: _____

Diagnoses/Past Procedures/Physical Exam continued:

Medications:	Significant baseline ancillary findings (lab, x-ray, EEG):
1. _____	_____
2. _____	_____
3. _____	_____
4. _____	Prostheses/Appliances/Advanced Technology Devices:
5. _____	_____
6. _____	_____

Management Data:

Allergies: Medications/Foods to be avoided	and why:
1. _____	_____
2. _____	_____
3. _____	_____
Procedures to be avoided	and why:
1. _____	_____
2. _____	_____
3. _____	_____

Immunizations

Dates						Dates					
DPT						Hep B					
OPV						Varicella					
MMR						TB status					
HIB						Other					

Antibiotic prophylaxis:	Indication:	Medication and dose:
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Common Presenting Problems/Findings With Specific Suggested Managements

Problem	Suggested Diagnostic Studies	Treatment Considerations

Comments on child, family, or other specific medical issues:

Physician/Provider Signature:	Print Name:
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MEDICAL TAB

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Medical / Dental Community Health Care Providers

• Primary Care Physician: _____

Date of First Visit: _____

Office Nurse: _____

Address: _____

Phone: _____ Fax: _____ Website/Email: _____

• Community Hospital: _____

Medical Record Number: _____

Address: _____

Phone: _____ Fax: _____ Website/Email: _____

• Medical Specialist: _____ Specialty: _____

Date of First Visit: _____

Address: _____

Phone: _____ Fax: _____ Website/Email: _____

• Medical Specialist: _____ Specialty: _____

Date of First Visit: _____

Address: _____

Phone: _____ Fax: _____ Website/Email: _____

• Dentist / Orthodontist: _____

Date of First Visit: _____

Address: _____

Phone: _____ Fax: _____ Website/Email: _____

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Therapists

Community Health Care / Service Providers

Therapists:

• Occupational Therapist (OT) _____

Start Date: _____

Agency: _____

Address: _____

Phone: _____ Fax: _____ Email: _____

• Physical Therapist (PT): _____

Start Date: _____

Agency: _____

Address: _____

Phone: _____ Fax: _____ Email: _____

• Speech-Language Pathologist: _____

Start Date: _____

Agency: _____

Address: _____

Phone: _____ Fax: _____ Email: _____

• Behavior Services (ABA): _____

Start Date: _____

Agency: _____

Address: _____

Phone: _____ Fax: _____ Email: _____

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Public Health Community Health Care / Service Providers

• Public Health Department: _____

Address: _____

Phone: _____ Fax: _____ Email: _____

Website: _____

• Public Health Nurse: _____

Address: _____

Phone: _____ Fax: _____ Email: _____

• Nutritionist: _____

Address: _____

Phone: _____ Fax: _____ Email: _____

• Social Worker: _____

Address: _____

Phone: _____ Fax: _____ Email: _____

• Other: _____

Address: _____

Phone: _____ Fax: _____ Email: _____

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Home Care

Community Health Care / Service Providers

• Home Nursing Agency: _____

Start Date: _____

Contact Person: _____

Address: _____

Phone: _____ Fax: _____ Email: _____

Website: _____

• Home Nursing Agency: _____

Start Date: _____

Contact Person: _____

Address: _____

Phone: _____ Fax: _____ Email: _____

Website: _____

• Home Nursing Agency: _____

Start Date: _____

Contact Person: _____

Address: _____

Phone: _____ Fax: _____ Email: _____

Website: _____

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Equipment / Supplies

• Name of Equipment: _____
Description (brand name, model, size, etc.): _____
Date obtained: _____ Supplier: _____
Website: _____
Contact Person: _____ Phone: _____
Serial Number: _____

• Name of Equipment: _____
Description (brand name, model, size, etc.): _____
Date obtained: _____ Supplier: _____
Website: _____
Contact Person: _____ Phone: _____
Serial Number: _____

• Name of Equipment: _____
Description (brand name, model, size, etc.): _____
Date obtained: _____ Supplier: _____
Website: _____
Contact Person: _____ Phone: _____
Serial Number: _____

• Name of Equipment: _____
Description (brand name, model, size, etc.): _____
Date obtained: _____ Supplier: _____
Website: _____
Contact Person: _____ Phone: _____
Serial Number: _____

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Pharmacy

Community Health Care / Service Providers

• Pharmacy: _____ Hours/Days of Operation: _____

Contact Person: _____

Address: _____

Phone: _____ Fax: _____ Email: _____

Website: _____

• Pharmacy: _____ Hours/Days of Operation: _____

Contact Person: _____

Address: _____

Phone: _____ Fax: _____ Email: _____

Website: _____

• Pharmacy: _____ Hours/Days of Operation: _____

Contact Person: _____

Address: _____

Phone: _____ Fax: _____ Email: _____

Website: _____

INSURANCE TAB

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Insurance/Funding Sources

• Insurance Company: _____
Policy Number: _____
Contact Person / Title: _____
Address: _____
Phone: _____ Fax: _____ Email: _____
Website: _____

• Insurance Company: _____
Policy Number: _____
Contact Person / Title: _____
Address: _____
Phone: _____ Fax: _____ Email: _____
Website: _____

• Insurance Company: _____
Policy Number: _____
Contact Person / Title: _____
Address: _____
Phone: _____ Fax: _____ Email: _____
Website: _____

• Supplemental Security Income (SSI): _____
Contact Person / Title: _____
Address: _____
Phone: _____ Fax: _____ Email: _____
Website: _____

EDUCATION TAB

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School Community Health Care / Service Providers

• School / Preschool: _____

Start Date: _____

Address: _____

Phone: _____ Fax: _____ Email: _____

Website: _____

• School Nurse: _____

Phone: _____ Fax: _____ Email: _____

• Contact Person/Title: _____

Phone: _____ Fax: _____ Email: _____

• Contact Person/Title: _____

Phone: _____ Fax: _____ Email: _____



What You Should Know

The I.E.P. Meeting

Your child should have an Individualized Education Plan (I.E.P.) meeting every year in order to review and/or develop the following:

- Present levels of performance
- Measurable annual goals (SMART Goals)
- Special education services provided
- Related services being provided
- Determination of the least restrictive environment
- Program modifications or accommodations
- Transition goals and services, if the child is 16 years or older.



SMART I.E.P. Goals

Specific

Measurable

Action-Driven (use action words)

Realistic and relevant

Time-limited

Example: By **October 15, 2015**, John will add **single-digit numbers** with **85%** accuracy in 8 out of 10 trials using touch math.

Related Services

- Speech and language therapy
- Occupational therapy
- Physical therapy
- Audiological services
- Vision therapy
- Orientation and mobility instruction
- Adapted physical education (APE)
- Mental Health services
- Health and nursing services
- Assistive technology
- Transportation
- Social skills training
- Behavior intervention services (ABA)

Least Restrictive Environment

- **General Education / Full inclusion** – child is in a regular education classroom with non-disabled peers 100% of the time.
- **Mainstreaming** – child spends some of the day within regular education setting.
- **Resource specialist program (RSP)** – child is fully included in most subjects, but is pulled out for extra tutorial assistance.
- **Special day class (SDC)** – classroom comprised of children with disabilities that need extra curriculum support.
- **County program**– examples include deaf and hard of hearing and emotionally disturbed classes.
- **Non-public school (NPS)** – school only with children with disabilities.
- **Home / Hospital** – children with medical needs that are unable to participate in classroom setting.
- **Residential treatment facility**

Safeguards

- **Compliance complaint -**
You can file against the school district when they have not followed special education laws or if they have not implemented what is already in your child's I.E.P.
 - ❖ Filed with the California Department of Education who will conduct an investigation.
- **Due Process -**
This is a legal procedure that ensues when there is a disagreement between you and the school district as to what should go in the I.E.P.
 - ❖ Often starts with mediation in an attempt to develop a resolution without having to go to hearing.
 - ❖ Mediation is optional.



Reminders to Parents

- You can request an I.E.P. meeting any time you have concerns.
 - The school has 30 days to schedule the requested I.E.P.
- Request copies of your child's assessments prior to the I.E.P. meeting to allow you to review and research.
- You can bring an advocate, attorney, or friend to the I.E.P. meeting.
- You can tape record your I.E.P. meeting (make sure to give written notice at least 24 hours in advance of I.E.P. meeting)
- Do not sign the I.E.P. unless you are completely satisfied.

SCDD Contact Information

State Council on Developmental Disabilities, Orange County Office
2000 East Fourth Street, Suite 115
Santa Ana, California 92705
Phone: (714)558-4404
Fax: (714)558-4704
E-Mail: christine.tolbert@scdd.ca.gov
scarlett.vonthenen@scdd.ca.gov

IDEA: Your Rights

Under the Individuals with Disabilities Education Act, your child is entitled to (in part):

- An annual IEP
 - You can request one any time
 - The school has 30 days to schedule the requested meeting (EC 56343.5)
- A free and appropriate public education
 - From ages 3 to 21 (sometimes to 22)
 - Includes related services
- Placement in the least restrictive environment

Valuable Publications

- **Disability Rights California**
Special Education Rights and Responsibilities
To order: (800)776-5746 (Donation only)
- **California Department of Education**
Composite of Laws
To order: (916) 319-0800 (Free)
- **CalSTAT**
Tools to Develop, Implement, and Score a Behavior Support Plan
To order: <http://www.calstat.org/> (Free)

NOTES TO TAKE TO THE INDIVIDUAL EDUCATION PLAN (IEP)

1. What are your chief concerns about you child? _____
2. What are you child's strengths? _____
3. It is important to put together a plan that is tailored for your child and not just your child's diagnosis, so please describe your child?

4. What is your child's diagnosis or qualifying condition? _____
5. Who diagnosed your child? _____
6. Who would you like to be at your child's IEP? _____
7. What would you like them to do at the IEP? _____
8. Notes: _____

LOCAL SERVICE AGENCY TAB

**ELIGIBILITY DETERMINATION GUIDELINES
FOR REGIONAL CENTER OF ORANGE COUNTY**
California's Early Start Program For Infants and Toddlers Birth to 3 Years

Eligible Conditions: California Code of Regulations (Title 17, Division 2 Chapter 2-Early Intervention Services SubChapter 1-General Provisions Article 2-Eligibility for California's Early Start Program Section 52022 Eligibility Criteria) defines eligibility for services to mean infants and toddlers from birth to age 2 (up to 36 months), for whom a need for early intervention services, as specified in the Individuals with Disabilities Education Act, and applicable regulations, (20 U.S.C. Section 1471 et seq.) is documented by means of assessment and evaluation and who meet one of the criteria listed below. TBL Section 2 and 3: Section 95014 Government Code beginning January 1, 2015.

I. DEVELOPMENTAL DELAY: Infants and toddlers with a developmental delay are children who have a delay in one or more of the following five areas: Cognitive development; gross and fine motor development, communication development; social or emotional development; or adaptive development. Developmentally delayed infants and toddlers are those determined to have a significant difference between the expected level of development for their age and for their current level of functioning. This determination shall be made by qualified personnel who are recognized by, or part of, a multidisciplinary team, including the parents.

- ▶ The diagnosis of developmental delay may be made after assessment using standardized assessment tools in addition to clinic observation and parent report.
 - ▶ A diagnosis of developmental delay does not qualify a child for regional center services after age 36 months.
 - ▶ Eligibility for services under the provisions of Part C Early Start based on "developmental delay" must be made only after careful review by the Eligibility Health Resource Group.
- (Infants and toddlers who are eligible under this category must show a 33% delay in one of five developmental areas.)

Cognitive Development

Cognitive delay is often associated and presents with delay in other developmental areas. Assessment should consider the infant/toddler's skills in memory, perception, imitative behavior, problem-solving; and in the older child (age greater than 24 months), verbal reasoning.

Physical and Motor Developmental (Including Vision and Hearing)

Physical and motor developmental delay is generally determined by failure to achieve motor developmental milestones within expected intervals, e.g., sitting at 6 to 8 months, walking at 12 to 15 months.

Communication Development (Speech and Language)

Children after 36 months with only communication delay will not be eligible for ongoing regional center services.

Social/Emotional Development

Children likely to be found eligible because of social and emotional delay usually have poor infant/parent-caregiver attachment and/or self-injurious behavior and typically present with more global delays relating to social interaction (e.g., Autism spectrum disorders – DMS IV).

Adaptive Development

Delay in the adaptive area is defined as delay in the acquisition of self-help skills such as feeding. Adaptive delay is usually interdependent with the other four areas of development.

II. ESTABLISHED RISK CONDITIONS: Children with established risk conditions are children with conditions of known etiology or with harmful developmental consequences. The condition must be:

- ▶ Diagnosed by a qualified clinician recognized by or part of a multidisciplinary team including the parents
- ▶ Known to have a high probability of leading to a developmental delay in one or more of the five developmental areas listed above.

Some conditions that may have established risk, depending on the exact clinical diagnosis or clinical course include: certain chromosomal and genetic disorders such as inborn errors of metabolism, certain congenital malformations, severe infections, especially of the central nervous system, certain neurological disease or trauma and poisoning or toxic exposure with neurological consequences.

III. HIGH RISK: High Risk for a developmental disability exists when a multidisciplinary team determines that an infant or toddler has a combination of two or more of the following factors:

- ▶ Prematurity of less than 32 weeks gestation and/or low birth weight of less than 1500 grams.
- ▶ Assisted ventilation for 48 hours or longer during the first 28 days of life.
- ▶ Small for gestational age: below the third percentile on the National Center for Health Statistics growth charts.
- ▶ Asphyxia neonatorum associated with a five minute Apgar score of 0 to 5.
- ▶ Severe and persistent metabolic abnormality, including but not limited to hypoglycemia, acidemia and hyperbilirubinemia in excess of the usual exchange transfusion level.
- ▶ Neonatal seizures or non-febrile seizures during the first three years of life.
- ▶ Central nervous system lesion or abnormality.
- ▶ Central nervous system infection.
- ▶ Biomedical insult including, but not limited to, injury, accident or illness which may seriously or permanently affect developmental outcome.
- ▶ Multiple congenital anomalies or genetic disorders which may affect developmental outcome.
- ▶ Prenatal exposure to known teratogens.
- ▶ Prenatal substance exposure, positive infant neonatal toxicology screen or symptomatic neonatal toxicity or withdrawal.
- ▶ Clinically significant failure to thrive, including, but not limited to, weight persistently below the third percentile for age on standard growth charts or less than 85% of the ideal weight for age and/or acute weight loss or failure to gain weight with the loss of two or more major percentiles on the growth curve.
- ▶ Persistent hypotonia or hypertonia, beyond that otherwise associated with a known diagnostic condition.
- ▶ High risk for a developmental disability also exists when a multidisciplinary team determines that the parent of the infant or toddler is a person with a developmental disability and the infant or toddler requires early intervention services.

IV. LOW INCIDENCE- means one or a combination of low incidence disabilities which are as follows:

Title 17 Section 52000-

Vision impairment or hearing impairment or orthopedic impairment
and
Cognition within normal limits

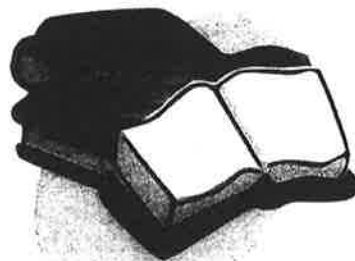
The above low incidence disabilities would have a significant impact on learning and development of the infant or toddler as determined by the IFSP team of the Local Education Agency.

RCOC is the central referring point agency for these children and will refer to Local Education Agency for ES Services. The infant or toddler who has a low incidence disability shall not be eligible for services from a regional center.

Mailing Address: P. O. Box 22010, Santa Ana, CA 92702-2010
Telephone 714-796-5100 (24 hrs) * Toll Free 800-244-3177* Fax (714)796-5200 * www.rcocdd.com

○ The Individualized Family Service Plan (IFSP)

An Individualized Family Service Plan (IFSP) is created for every child enrolled in Early Intervention (EI). EI staff works with the family to develop it. The IFSP includes assessments of the child and descriptions of both family needs and strengths. It also lists all the education, training, therapy and support services the child and family will receive and who will deliver these services.



As your child approaches age 3, your Regional Center Service Coordinator will coordinate the referral and transition conference with your school district, should special education preschool be appropriate. This referral can help your child transition from Early Intervention services to the education system.

Tip:

Keep copies of your child's IFSP with other care plans.



We're Here for You

The Regional Center of Orange County (RCOC) is Orange County's focal point for providing individualized services to people with developmental disabilities (also referred to as consumers). We provide lifetime supports to more than 18,000 Orange County consumers through assistance with locating and using programs, service coordination as well as information and referral to other resources.

One of 21 regional centers founded in 1969 as a result of the passage of the Lanterman Developmental Disabilities Act, RCOC is the non-profit agency designated by the State of California to provide information and services to Orange County residents who have a developmental disability, who may be at risk of having a child with a developmental disability or who have given birth to a child with a developmental disability.

According to State law, a person is eligible for RCOC services if all of the following criteria are met:

- ▶ the person has a disability due to intellectual disabilities, cerebral palsy, epilepsy, autism or a condition requiring treatment similar to that required by a person with intellectual disabilities;
- ▶ the disability began before the age of 18;
- ▶ the disability is likely to continue indefinitely;
- ▶ the disability is substantially handicapping for the individual.

Any resident of Orange County who has or is suspected of having a developmental disability that originated before age 18 is entitled to receive an assessment to determine eligibility. RCOC also coordinates the State-mandated Early Start Program which provides services for children under age 3 who have or are at substantial risk of having a developmental disability.

Following assessment, RCOC assigns a trained service coordinator to the individual's case. Services are offered to consumers based on person-centered Individual Program Plans and may include: adult day programs; assessment/consultation; behavior management programs; day care supplementation; diagnosis and evaluation; early intervention programs; independent living services; information and referrals; mobility training; residential care; respite care; physical and occupational therapy; transportation; consumer, family and provider training; and vocational training. The phone number for our Intake Department is 714-796-5354.

We have two locations and 24-hour emergency service to be more accessible to the people we serve. **All locations can be reached 24 hours a day via phone (714) 796-5100 or fax (714) 796-5200.**

Santa Ana
1525 N. Tustin Ave.
TDD: 714-667-6021

Cypress
10803 Hope Street
TDD: 714-889-5789

Mailing Address: P. O. Box 22010, Santa Ana, CA 92702-2010
Telephone 714-796-5100 (24 hrs) * Toll Free 800-244-3177 * Fax 714-796-5200 * www.rcocdd.com



I.P.P. Basics



What You Should Know

The I.P.P. Meeting

Typically, a consumer's Individual Program Plan (I.P.P.) meeting is held annually at the consumer's home, or another mutually agreed upon location, in order to review present levels of performance and to develop new goals in the areas of:

- living options
- health and medical
- school / employment / vocational
- behavioral health
- daily living needs
- social / recreational
- financial / money management
- emergency preparedness
- futures planning

Regional centers fund services based upon a consumer's needs and corresponding goals. Therefore, it is essential to give your service coordinator an updated and accurate reflection of the consumer every year. Remember to talk about:

- strengths
- abilities
- accomplishments
- future goals
- areas of concern and areas of need

Regional center typically send the consumer the I.P.P. report within 45 days of the meeting. It is very important to take the time to read it carefully, as it is a legal document that will control services and supports for the entire year.

The consumer's I.P.P. needs to include:

- his/her needs, preferences, and choices
- measurable desired outcomes (goals)
- plans on how to achieve the desired outcomes
- authorized services with a contract number

If you do not receive the I.P.P. in the mail, send a written request to your service coordinator.

If you do not agree with something in the I.P.P. report, immediately notify your service coordinator and request the necessary changes in writing.

Do not sign the I.P.P. until you agree with the report or note on the I.P.P. that you do not agree with specific sections.

★ Note that regional centers may review consumer eligibility every 3 years.



The I.P.P. Team

The I.P.P. team consists of:

- consumer
- conservator or guardian
- parents
- care provider
- regional center service coordinator
- regional center decision-maker

★ Note that unconserved adult consumers may decide who participates at the meetings.

Reminders to Parents

You may...

- request an I.P.P. meeting any time you have concerns
- bring an advocate, attorney, or friend to the I.P.P. meeting
- tape record the I.P.P. meeting (WIC 4646.6)

You should...

- maintain a communication log book to track important phone calls / messages
- put all service-related requests in writing
- keep all documentation in one place

I.P.P. Basics - What You Should Know

Services Offered

- Adult day programs
- Behavior intervention services (ABA)
- Crisis intervention services
- Day care (through age 17)
- Durable and nondurable medical equipment
- Independent or supported living services
- Licensed residential services (board and care, group home placements)
- Medical and dental services
- Parenting classes (for consumers who are parents)
- Personal assistance
- Psychological assessments (for adults only)
- Respite care
- Supported employment
- **Special education advocacy clinic referrals** (Whittier Law School)
- Transportation services

This is a sample list of services and supports.



Safeguards

If you disagree with a regional center decision, you may request any one of the following to remedy the situation:

- **Planning Team/I.P.P. Meeting** – informal meeting that includes the consumer's service coordinator and a supervisor/decision-maker.
- **Informal meeting** – optional "first-step" meeting through the fair hearing process that includes regional center's fair hearing representative.

Safeguards Continued

- **Mediation** – optional meeting through the fair hearing process and typically considered the "second-step" in the process. This meeting includes the regional center fair hearing representative and an administrative law judge from the Office of Administrative Hearings (OAH) as the mediator.

- **Fair hearing** – legal proceeding whereby an administrative law judge hears both sides of the case and makes a final decision.

★ The informal meeting and mediation are optional. You may request the fair hearing only.

Contact Information

State Council on Developmental Disabilities

Orange County Office

2000 East Fourth Street, Suite 115

Santa Ana, California 92705

Phone: (714) 558-4404 Fax: (714) 558-4704

Website: www.scdd.ca.gov

E-mail: christine.tolbert@scdd.ca.gov

scarlett.vonthenen@scdd.ca.gov

Valuable Resources

- **Association of Regional Center Agencies**
Website: www.arcnet.org
- **Department of Developmental Services**
Lanterman Developmental Disabilities Services Act and Related Laws (2010 version online)
To order: (916) 654-1897 (Free)
Available on-line at www.dds.ca.gov
- **Disability Rights California**
Rights Under the Lanterman Act (2006)
To order: (800)776-5746 (Donation requested)
Available on-line at www.disabilityrightsca.org
- **Regional Center of Orange County (RCOC)**
Phone: (714) 796-5100
Website: www.rcocdd.com

RESOURCES TAB