

One Step at a Time
Transition to Adult Services
Workbook for Parents

Compiled by:

Jarice Butterfield, Ph.D.

Santa Barbara County SELPA Director

Adapted from the Sacramento County SELPA's Transition Workbook

*“Serving Families and Professionals Involved with
Children with Special Needs.”*

In

Santa Barbara County

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Introduction - A Note to Parents and Guardians

Transition involves moving from one place, stage or relationship to another. Transitions happen throughout every person's lifetime. Change can be stressful, but with preparation, support, information, and planning, transition to adult programs and services can be made easier for you and your teen with special needs.

Children with special needs (and their families) experience more frequent and some times more challenging transitions than do typically developing children for various reasons such as change of providers (teachers, therapists, case managers, etc.) who might have been providing guidance and support for years and who might seem part of the family. You, the parent, are the constant in your child's life and can provide the link between your teen and all of the various services, programs, and people who have provided those services in the past and who will provide those services in the future. Your knowledge of the needs of your family and teen can help his or her transition(s) to succeed and we hope you use this workbook as a tool for that success.

"One of the most striking (and most stressful) aspects of transition for families of children with exceptional needs is that it focuses on relationships: beginning and ending them, leaving a comfortable situation and starting all over again."

Brekken & Knowlton, Transition Issues: A Model for Early Childhood Special Education

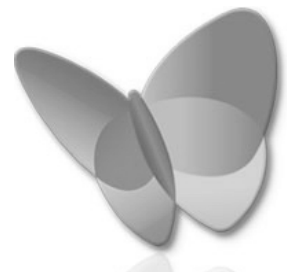
This workbook has been prepared for you by Santa Barbara County SELPA to help you and your teen prepare for transition from high school into the adult world. While students usually leave high school at age 17 or 18, most parents who have been through the process agree that the earlier you and your teen start exploring options, the better. Teens typically face another transition period at age 22 when they no longer receive special education services and they may "age out" of other programs. The passage of your teen into adulthood is an exciting time, but can also be worrisome as you face an array of options, services and providers that are new to you. This booklet is not inclusive in its resources, but was written to give you as much information in a "one stop" format as possible. Good luck to you and your teen as you travel this wonderful road of growth and discovery into adulthood.

Many thanks to the many parents and professionals who contributed to this booklet. Your input has been invaluable!

Thanks most of all to our children...you're the lights of our lives and our fondest wish for you is that you are able to spread your wings and fly!

Support Network

As the parent of a child with special healthcare and/or developmental needs, you probably have developed a support network—a group of people who can assist you by offering resources, advice and information. As your teen transitions to adult services many of these support people will be replaced by new ones. It's a good idea to make note your contacts within new agencies and new support people so that you know where to turn in times of need. Inside the back cover of this booklet, you will find a page for frequently called numbers.



"My son is now 21 years old and I feel as though I've been in denial about what types of programs I should have been looking for when he was a teen. I wish that when he was younger I had known what questions to ask. Now I feel like I'm playing "catch up".

Preparing for the Future

(Adapted from "Parent Guide: What Parents & Families Need to Know about Transition Education and Planning: An Insiders' Perspectives by John R. Johnson, PhD.)

Things that you can do with your teen early-on to help him/her be a successful adult:

- The transition IEP at age 16 should never be the starting point for transition planning - **You and your teen** are the starting points and the sooner you start thinking and talking about transition, the more confident you will both feel about it.
- Develop with your teen a vision of what he or she would like to be doing as an adult. (Assure him or her that the vision is not "written in stone" and that it is O.K. if it changes over time.). Discuss where he or she would like to live, work and who his or her friends might be.
- Encourage your child from an early age to have hopes, dreams and aspirations for the future and communicate them to family, teachers and anyone else who works with him or her.
- Ask your teen about his or her likes, dislikes, interests, choices, preferences and strengths.
- Encourage your teen to create a biographic portfolio that describes his or her experiences which are related to work, social relationships, leisure/recreation, family, church, in the community, school and friends.



Tri Counties Regional Center

The Regional Center system in California serves individuals with developmental disabilities and their families. In Santa Barbara County, the Regional Center is the Tri Counties Regional Center. Tri-Counties contracts with agencies and individuals who provide a wide variety of services, including developmental services, respite, supported employment and help with supported living arrangements. To view <http://www.tri-counties.org/tcrc3/programs-services/social-activities/santa-barbara.htm>

According to the Lanterman Developmental Disabilities Act (AB 846), "developmental disability" means a disability attributable to; mental retardation, cerebral palsy, epilepsy, autism, or other handicapping conditions found to be closely related to mental retardation or to require treatment similar to that required for mentally retarded individuals. Such a disability originates before an individual reaches age 18, continues or can be expected to continue indefinitely, and constitutes a substantial handicap for such individuals. ("Substantial handicap" means a condition that results in major impairment of cognitive and/or social functioning.)

The Lanterman Developmental Disabilities Act requires that a person over three years old who receives services from a regional center have an Individual Program Plan (IPP). The IPP is updated annually by the consumer's service coordinator using person-centered planning. Person-centered planning is about listening to consumers (and their families) about things such as where they want to live; how they want to spend their day; who they want to spend time with; and their hopes and dreams for their future. It is about supporting people in the choices they make about their lives and giving people the information they need to make those choices. After the service coordinator helps write the IPP, he or she looks for services and supports when needed, and makes sure that the services that the consumer gets are the ones needed and wanted.

A booklet titled, "Your IPP - It's Not Just a Piece of Paper! A Self-Advocacy Manual for People Who Get Services from Regional Centers" which is available on the Protection and Advocacy website at ww.pai-ca.org/PUBS/503801.pdf contains valuable information about the IPP process and how to prepare for the IPP meeting. It is also available from Capitol People First at 916-486-2657 or 916-381-1300 ext. 145. (See the end of this booklet for an "IPP Meeting Planner").

Transition Services in High School

When a student who has an Individualized Education Plan (IEP) enters high school, one of the most important decisions to be made is whether he or she will graduate with a diploma (which will end special education services), or leave high school with a certificate of completion, which will allow special education services to continue until the teen reaches the age of 22.

If the student leaves high school with a certificate of completion, then it is vitally important that you and your teen continue to work closely with the IEP team to identify the goals that will help support as much independence as possible as he or she faces transition out of special education services.

California requires that in order to graduate high school with a diploma, students must pass the California High School Exit Exam (CAHSEE). To find current information on the CAHSEE, contact your Special Education Local Plan Area (SELPA) at 805-683-1424 or local school district.

School districts are required, under special education law, to begin transition planning when the student is 16. However, most parents who have had teens with special needs agree that the earlier you start thinking and working on transition issues, the better prepared your teen (and you) will be for adulthood.

Transition IEPs should include:

- Adult goals with measurable outcomes identified; including making choices and decisions, problem solving, goal setting and attainment, self advocacy, involvement and participation in IEP, self-awareness and self-management,
- Goals/outcomes that identify what instruction will be provided at school and in the community,
- Instruction directly related to adult goals/outcomes in areas of curriculum based on the student's preferences, interests and priorities,

- A range of educational opportunities that are sufficient to encourage the development of the student's choices, interests, preferences and options for the future,
- The opportunity for paid work experience,
- The opportunity for both academic and community based/independent living skills curriculum,
- The opportunity for the student to be included with non-disabled peers,
- Statement(s) of transition services needs,
- Identification of other agencies involved with transition, i.e., Tri Counties Regional Center, Department of Rehabilitation.

By law, the student must be given the opportunity to participate in the transition IEP process!

Exploring Options for the Future

Making decisions about your teen's future can feel frightening and sometimes overwhelming. Transition to adult services can mean huge changes in both your lives and can make you both feel as though you're entering the unknown.

Your support network will be able to assist you in planning for your teen's transition to adult services. Teachers, Counselors, CCS Therapists, Tri-Counties Regional Center staff, agencies such as Department of Rehabilitation and advocates can also help you to plan for the future by providing you with resources about available services.

Things to think about include:

Where your teen will live:

- At home with you,
- In a group home,
- Independently (with or without supportive services like attendant care)



What will your teen will do all day:

- Go to college,
 - Attend vocational training,
 - Attend a supported employment program,
 - Attend a day program,
 - Work at a job.



What financial assistance will your teen will receive as an adult:

- SSI
- IHSS

Who will provide medical care & coverage:

- Private Insurance—If you have private insurance, find out if your teen will continue to have it after age 18.
- Medi-Cal—Apply when your young adult is 18.

Will your teen need help making decisions as an adult? From whom?

- Parents or other family members,
- Alta California Regional Center Service Coordinator,
- Conservator.



Getting Help When You Need It

There are agencies available to help you get transition services and advocate for your teen. Many of the same people who have helped you all along will still be a part of your team. For those people who cannot continue in the role of support you will want to find and develop new resources to take their place.

Sources of support include:

- Area Board IX: <http://www.areaboard9.org/> - 805-685-8395
7127 Hollister, Suite 7 Goleta, CA 93117
- Health Rights Hotline: 916-551-2100 / 888-354-4474
- Tri Counties Area Protection & Advocacy: 805-884-7297
- Independent Living Resource Center (ILRC): (805) 963-0595
- Family First at Alpha Resource Center: (Santa Barbara) - 805-683-2145 www.alphasb.org
4501 Cathedral Oaks Rd
Santa Barbara, CA 93110



The job of all parents is to help their child become as independent as possible. Like any other child, your teen with special needs will need to learn many self help skills for the adult world. Not all of the skills we have listed will be something that every child can achieve. The following worksheets are meant as general guidelines for you to use to give yourself a better idea of skills your teen currently has or needs to work on. The worksheets cover various topics, skills and resources your

teen will need for the future. Your teen may already be working on many of these skills in school. If you aren't sure how to go about helping your teen learn a skill, talk with his/her teacher or your Tri Counties Regional Center Service Coordinator for help. Also, check out the expanded list of resources at the end of this workbook for people and agencies that can help you.

Helping Your Teen to Independence

Medical Care/Health Skills			
<i>Skill</i>	<i>Can Do Independently</i>	<i>Can Do W/ Help</i>	<i>Needs Someone To Do This</i>
Describe his/her medical condition(s)			
Understands how his/her special need affects daily life			
Can prepare and ask questions of health care providers			
Knows: <ol style="list-style-type: none"> 1. The medications he/she takes 2. When to take them 3. What they are for 4. How to refill them 			
Can perform own treatments, therapy or exercises			
Can manage own diet			
Can call or go on-line to make appointments for medical or dental care			
Can recognize signs & symptoms which require a doctor or dentist visit, such as infection, breathing problems, skin breakdown, urinary tract infection, high fever, allergic reaction, toothache			
Can recognize signs & symptoms of medical emergency and can activate EMS (Emergency Medical System)			
Knows what equipment he/she uses, what it does and who to contact for repairs			
Understands basic sexuality concepts			

Insurance			
<i>Skill</i>	<i>Can Do Independently</i>	<i>Can Do W/ Help</i>	<i>Needs Someone To Do This</i>
Knows insurance plan name, address, case manager contact information and is responsible for insurance ID card			
Providers			
Knows names of primary care providers (dentist, specialists) and how to contact			
Knows how to make medical appointments			
Knows how to order medications from pharmacy, equipment from providers, etc.			
Keeps summary medical file			

Independent Living/Self-Advocacy			
<i>Skill</i>	<i>Can Do Independently</i>	<i>Can Do W/ Help</i>	<i>Needs Someone To Do This</i>
Interview, hire, instruct, evaluate, terminate attendant			
Has appropriate social skills			
Understands about inappropriate touching or actions and who to tell if it happens			
Has driver's license or state ID card			
Able to pay for item(s) in store or restaurant			
Able to use public transportation			
Has safe, affordable housing			
Can budget money and pay bills			
Self Care			
Use toilet (clean, intermittent catheterization or bowel program)			
Shower or bathe			
Brush teeth			
Brush hair			
Inspect skin for breakdown			
Mobility			
Ambulate independently			
Ambulate with use of aids			
Use wheelchair independently			
Transfer			

Eating			
<i>Skill</i>	<i>Can Do Independently</i>	<i>Can Do W/ Help</i>	<i>Needs Someone To Do This</i>
Feed self			
Shop for food			
Cook food			
Dressing			
Dress independently			
Choose appropriate clothing for occasion and weather			
Household Chores			
Launder clothes			
Wash dishes			
Make bed			
Use telephone			
Jobs & Post-Secondary Education & Training			
Can use a computer, search the internet, word process			
Can advocate for self regarding accommodations needed in school, work, community or home			
Has a resume			
Can complete a job application and can interview for a job			
Has obtained vocational training or performed volunteer service			
Has developed the interpersonal skills necessary to maintain employment			
Knows how to apply and register for college			
Knows how to access disability support and counseling services			
Recreation & Leisure			
Has developed a variety of recreation & leisure skills			
Has spectator or audience member skills			
Can identify affordable recreation & leisure activities			
Can arrange social activities			
Has identified social supports through family, peer group, mentors, community resources			

Transitioning to Adult Medical Care

"My daughter is 15 years old and has lots of medical needs. I worry about where to find doctors who understand her medical issues, can work with someone who is developmentally delayed...and who are accepting new Medi-Cal patients!"

When your teen turns 18 most medical payers will require that he or she switch to adult service providers. There are some things that parents can do in advance to make the transition smoother.

- Find out the policies regarding age and service limits for your teen's current doctors.
- Check with your insurer regarding the age limit of services under pediatric/adolescent care.
- Begin discussing transition with your child and health care providers at the age of 16.
- Work to teach your child to take charge of his/her health care services.
- Ask your pediatric/adolescent care provider to recommend an adult provider who is sensitive and knowledgeable of special health care needs and disabilities.
- Find out how your insurer handles referrals and consultations for transition to adult health care.
- Check with your insurance on how long they will cover your child. The policy may have age limitations.
- Check into Medi-Cal if your teen does not currently have it.
- Be aware that you may have to seek medical care for your adult child at a larger medical center where there are more likely to be more medical subspecialties.
- If your child does not already have a medical alert bracelet, consider ordering one so that emergency personnel can readily access health information. (This is also a useful tool in case the person becomes lost or disoriented.)
- If your child has extensive medical needs, you might want to explore your state's legal requirements about limited guardianship. This will allow you to make health care decision if he/she is unable to do so independently.

How to Help Your Teen be a Good Health Advocate

Teens with developmental disabilities may not be able to manage their health care independently; however, the goal is to make them *as independent as possible* by helping them to acquire as many self-advocacy skills as possible.

In order to be a good health advocate, your teen should:

- Know as much as possible about his or her diagnosis.
- Learn warning signs that mean emergency help is needed.
- Know who to call in an emergency.
- Keep track of appointments, be on time and be prepared.
- Write down questions for doctors before going to the appointment.
- If your teen doesn't understand something that health care providers say, ask them to clarify it - put things in terms that he or she can understand. Never be afraid to ask questions!
- Ask for copies of medical tests or reports for home medical file.
- Carry copies of his/her insurance card and other health care information.
- Know the medication(s) that he or she takes, the name(s) of the medicines, why they are taken, how much to take and when they should be taken.
- Keep a list of phone numbers and addresses of all doctors, clinics and hospitals.
- You and your teen should meet and talk with the new adult care doctor before switching. Find someone with whom both you and your teen are comfortable.

If you are having a problem with your teen/young adult's health care or have questions about Medi-Cal, Healthy Families, or private insurance, contact:

- Health Rights Hotline at 916-551-2100 / 800-354-4474

Questions to Ask a New Health Provider

Before your teen becomes a patient of a new health care provider, you may want to set up an appointment to meet and ask questions. Write your questions down and take them with you. You may want to include some of the following questions:

- Have you ever had a patient with special health care needs similar to my teen's?
- Are you able/willing to talk with my teen's pediatrician/adolescent health care provider to gain an understanding of his/her unique health issues?
- Do office visits include a time to talk with you about any concerns?
- Is your office accessible to someone who uses adaptive equipment?
- Are you comfortable providing care for my teen that has special health care and/or developmental needs?

Helping Your Teen Schedule & Keep Medical Appointments



Depending upon your teen's physical and cognitive skills you can teach him or her to take charge of medical and other appointments as much as possible. Adapt the following for your teen's skills and abilities.

Parents can help their teens learn to schedule and keep appointments by encouraging them to do it themselves. If your teen is able to use the phone, teach him or her how to look up the phone number of the person they need to call. You may want to put frequently used numbers into the phone's memory, or post them in an accessible place near the phone.

Teach your teen to give his or her name and tell why he or she is calling, " My name is John Smith and I'm calling because I have a sore throat and I need an appointment to see the doctor". Make sure that he or she has any information such as a medical record number or Medi-Cal number before calling. Have your teen write down the appointment date and time on a calendar. If your teen is unable to use a phone but can use a computer, find out if the doctor or other provider has an e-mail address and will make appointments that way.

Help your teen to keep track of appointments with a personal digital assistant (PDA), calendar or even notes tacked up around the house. You may also consider a large day planner posted in an accessible place and using different colored markers or stickers so that your teen can tell at a glance what needs to be done that day.

Teach your teen to plan ahead - (Helping your teen to learn these skills now will make them more independent in the future.)

- How will he or she get to the doctor's? Get a ride from parents? Take public transportation or Paratransit or get a ride from a friend?

- What time will he or she need to leave in order to arrive at the appointment on time?
- What will he or she need to bring?
Bus fare? Cell phone?

Medical ID card?

Money or other payment options?

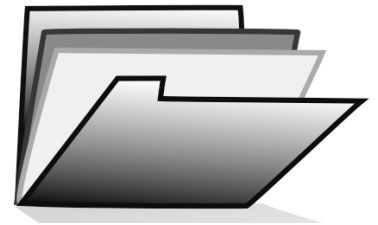
Medical Record Keeping

Parents already know the importance of keeping good records. If possible, teens with special needs can start practicing keeping records that they will maintain as adults. Teach your teen to save receipts, medical reports and financial information. Even if it is just handing you a receipt to file, your young adult is learning that it is important to keep track of these items.

The personal medical file and diagnosis information that your teen maintains can be in the form of a file, a binder or kept on a computer.

Include in this:

- Medications taken, the dosage, how often and what for. Also include any precautions such as, "this medicine cannot be taken with pineapple juice" ,
- Medical insurance information or coverage, including the name of the health care plan, medical record number or card number,
- A list of doctors' names and contact numbers,
- Contact names and numbers for durable medical equipment vendors and a list of equipment or supplies,
- Social Security number,
- Diagnosis information,
- Medical records.



*"My daughter will not be able to maintain her extensive medical records by herself.
Is there help with this?"*

Medic Alert, the company that provides bracelets and medallions that can be worn to alert emergency personnel and healthcare providers of a medical condition, also offers programs for tracking and managing a person's medical records. For more information, contact Medic Alert at 888-633-4298 (<http://www.medicalert.org>)

Resources for Health Care Services

Access for Infants and Mothers (AIM)

✓ Description:

Health coverage for *pregnant women and newborns* (age birth to two). Designed for middle-income families who lack health insurance and whose income is too high to qualify for no-cost Medi-Cal. AIM is also available to those with health insurance if the maternity-only deductible of co-payment is more than \$500.

✓ Services:

- Physician visits



- Hospital newborn nursery services
- Prescriptions
- Diagnostic testing
- Medical equipment
- Well-baby care
- Emergency services
- Mental health services
- ✓ Eligibility:
 - Pregnant women (not more than 30 weeks)
 - California resident for the last 6 months
 - Not on Medi-Cal or Medicare
 - Cannot have maternity benefits through private insurance
 - 200-300% Federal Poverty Level (FPL)
- ✓ How to Apply:

The application is completed and sent in by mail. To request an application call 800-433-2611.

Web site: www.aim.ca.gov/english/AIMhome.asp

California Children's Services (CCS)

- ✓ Description:

A county-administered program that pays for specialty health care for children *birth to 21* with eligible medical condition(s). Services are provided by health care professionals who are approved by the State CCS program at Special Care Centers and Medical Therapy Program sites located on public school campuses.
- ✓ Services:
 - Diagnostic evaluations if a CCS - eligible diagnosis is suspected
 - Treatment services (hospitalizations, surgeries, social services,
 - Nutrition
 - Consultation, equipment, supplies, medications, orthodontics)
 - Therapy (Occupational and/or Physical)
- ✓ Eligibility:
 - Must be under age 21
 - Meet residential requirements
 - No income eligibility for therapy or diagnostic evaluation, but for treatment services, must be enrolled in Medi-Cal, Healthy Families, have an annual family income of less than \$40,000 or will expend more than 20% of annual family income on treatment of the CCS condition.
 - Have a CCS-eligible condition:
 - AIDS
 - Cancers, tumors
 - Cataracts
 - Cleft lip/palate
 - Cerebral palsy
 - Diabetes
 - Fractures (certain types)
 - Heart disease (congenital)
 - Hearing loss
 - Hemophilia
 - Intestinal diseases
 - Liver diseases

Muscular dystrophy
Premature birth (problems)
Rheumatoid arthritis
Seizures (uncontrolled)
Serious chronic kidney problems
Severe head, brain or spinal cord injuries
Severe burns
Severely crooked teeth
Sickle cell anemia
Spina bifida
Thyroid problems

✓ How to Apply:

In Santa Barbara County, call for application information -(805) 681-5131
California Children Services, 1111 Chapala Street, Suite 200, Santa Barbara, CA 93101
Website: http://www.sbcphd.org/cms/ccs_referral.html

Dental Health Services

✓ Description:

Provided through several programs in California (depending upon qualification), including CHDP, Medi-Cal, CCS, Healthy Families, and Tri-Counties Regional Center.

⇒ CHDP/Denti-Cal: Children and young adults who are eligible for Medi-Cal or CHDP may receive dental services from a provider who participates in Denti-Cal. Services include annual preventive dental care for eligible people three years of age and older. Call 800-322-6384 to apply.

⇒ CCS: (For children who do not have Medi-Cal) Dental and orthodontic services are provided if they are related to the treatment of the CCS-eligible condition or if the CCS-eligible condition would complicate routine dental care. Services include preventive and restorative services and general anesthesia when administered in a CCS-approved facility. (805) 681-5131, website http://www.sbcphd.org/cms/medical_therapy.html or contact the case manager if the child already has CCS services.

Genetically Handicapped Persons Program (GHPP)

✓ Description:

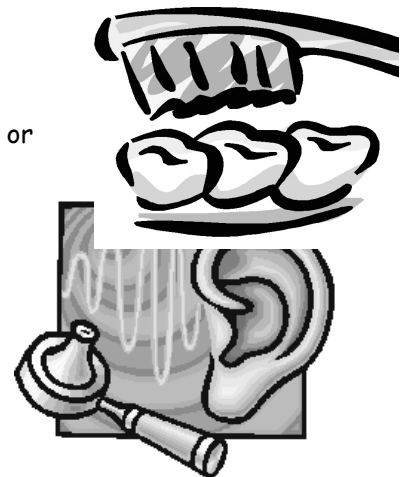
State program which provides medical case management and covers the medical and dental costs of individuals 21 years and over who have genetic diseases including cystic fibrosis, hemophilia, sickle cell disease, and other neurological and metabolic diseases.

✓ Services:

- Medical treatment and case management

✓ Eligibility:

- Individuals age 21 and over with genetic conditions who are partially or wholly unable to pay for care
- Individuals under 21 with eligible conditions if they are financially ineligible for CCS



- ✓ How to Apply:
Call 800-639-0597 or 916-327-0470.
Web site://www.dhs.ca.gov/pcfh/cms/ghpp/

Hear Now

- ✓ Description:
Provides assistance to individuals and families with limited financial resources. Maintains the National Hearing Aid Bank, which provides new and reconditioned hearing aids to deaf and hard of hearing people who cannot afford them. These hearing aids are distributed through hearing health care providers in communities nationwide. Hear Now also has a cochlear implant program and related service for both adults and children. In addition, Hear Now has developed the National Hearing Assistance Directory (NHAD), which provides state-by-state listings of financial and social resources offered through government agencies and private organizations.
- ✓ Contact: 800-648-4327

Medi-Cal

- ✓ Description:
California's "Medicaid" program and provides health insurance for low-income families and children who lack health insurance. Services may be obtained from any physician, clinic, or hospital that is a state-approved Medi-Cal provider. There are several forms of Medi-Cal services:
 - Fee-for-Service ("Straight") Medi-Cal: For those in foster care or who receive Supplemental Security Income (SSI). Recipients can go to a Medi-Cal provider and receive services without having to go through a health plan.
 - Medi-Cal Managed Care: Medi-Cal recipients receive health care from a state-approved health plan. Recipients may select a health plan and physician. Allows members to change doctors or health plans. Care is coordinated by the primary care physician. SSI recipients can choose either Managed Care or Straight Medi-Cal. Others must choose a Managed Care Plan.
 - Share-of-Cost Medi-Cal: Health coverage for individuals and families whose incomes are too high to qualify for regular Medi-Cal but too low to meet health care costs. The member pays a share-of-cost to the provider for services received.
 - Medi-Cal Waiver Services: A federal waiver which allows the state to disregard portions of the Social Security Act and provide Medi-Cal to individuals who may not otherwise be eligible.
 - Emergency Medi-Cal: Can be provided to individuals who would otherwise be ineligible due to immigration or other restrictions.
- ✓ Services (Not all of these services may be available with Emergency Medi-Cal):
 - Doctors' visits
 - Equipment and supplies
 - Hospital inpatient care
 - Laboratory tests
 - Medical transportation
 - Outpatient care
 - Pharmaceuticals
 - Skilled nursing care
 - X-Rays



✓ Eligibility:

- Individuals receiving public assistance:

CaLWORKS

SSI/SSP

Refugee Assistance

Foster Care or Adoption Assistance

- Some individuals who are low-income but do not otherwise qualify for Medi-Cal
- Medically needy or indigent (those whose income is too high to qualify for cash assistance but qualify for CaLWORKS or SSI/SSP)
- Low-income pregnant women, children under 21, adults in long-term care
- Pregnant women and infants in families with incomes at or below 200% of the Federal Poverty Level (FPL)
- Children aged 1-5 in families with incomes at or below 133% of the FPL
- Children aged 6-19 in families with incomes at or below 100% of the FPL

✓ How to Apply:

Automatically eligible if receiving SSI/SSP. Children and pregnant women may enroll via a mail-in application. Assistance is provided by an eligibility worker who will collect documentation to verify income and other information. Applicants are notified of their status within 45 days of application.

Go to <http://www.medi-cal.ca.gov/> for more information about Medi-Cal or call (800) 541-5555 or

Go to <http://www.healthyfamilies.ca.gov/English/about.html> for information on California Health Families medical services

Mental Health Services

✓ Description: Children and young adults with special health care or developmental needs may be eligible to receive mental health services through more than one program; therefore, care coordination is extremely important. The primary sources for mental health services are listed below.

AB 3632/ Chapter 26.5: This program combines special education services (age 3-22 years) with services provided by the Santa Barbara County Mental Health Services. It is available to students who qualify for special education services and who have been determined to need mental health treatment to benefit from their educational services.

A written referral from the regular education staff or a dated letter requesting assessment from the parent should be sent to the Special Education Department of the child's school district.

Medi-Cal Managed Care: Mental health services are available through a managed care plan for children whose mental health needs are not related to a diagnosis of emotional disturbance (ED). The referral must be made by the child's primary care provider. Call (805) 681-5220

Planned Parenthood

✓Description:

Provides family planning and primary care information and services including birth control, pregnancy testing and options counseling. HIV testing, cancer screening, testing and treatment for sexually transmitted infection for men and women, prenatal and postpartum care, child and adult immunizations.

518 Garden Street Santa Barbara, CA 93101

Clinic Phone Number: (805) 963-5801

Medication Assistance

▪ Needy Meds

www.needymeds.com

▪ National Organization of Rare Disorders (NORD)

www.rarediseases.org/programs/medication

203-744-0100 or 1-800-999-6673 (voicemail only)

▪ Pharmaceutical Manufacturers Association

www.rxhelpforca.org

877-777-7815

▪ RX Outreach-Volunteers in Health Core

www.Rxassist.org

877-844-8442



College

Disabled Students' Programs and Services (DSPS)

"My daughter has severe cerebral palsy and just graduated from U.C. Berkeley. She's so bright - but she needed the support that she received from DSPS there."

Students with special needs who continue on to higher education have a number of services available to them. Upon admission to college, the student should contact the DSPS office which will refer the student for services. Every public and private community college, college, and university has a DSPS office.

Services:

- Priority scheduling
- Registration assistance
- Classroom accommodations
- Alternate course assignments
- Large type print
- Learning disability services
- Mobility services
- Note-taking

✓

Eligibility: =

Students with a disability must submit verification when registering with the DSPS office. Criteria used to verify the diagnosis will depend on the diagnosis. It is helpful to have copies of medical records. Depending on the disability, students will be eligible for one or more services.

✓ How to Apply:

Ideally, students will self-refer to the DSPS office of the campus they wish to attend. Students transitioning from public school districts should be provided assistance as part of their IEP.

DSPS Departments:

- Santa Barbara City College DSPS: 805-962-4084 or Email: dspshelp@sbcc.edu
- Hancock College, 800 South College Drive (805) 922-6966 x 3247
- University of California Santa Barbara: 805) 893-2668 or <http://www.ucsb.edu/>

Vocational/Employment Programs

"My daughter thoroughly enjoyed the training at a bakery that she received through the (vocational education) program at her high school. I encourage families to consider those opportunities in high school in their resource options."

You and your teen should include transition team members in the discussion about what type of vocational training is right for your teen. While in high school, the district's transition or vocational training specialist can help arrange for your teen to be trained in any number of jobs that might interest him or her. (And sometimes, depending upon the program, it might include a paid position!) Other members of the team while your teen is still in high school might include his/her Tri Counties Regional Center service coordinator and a representative from the California Department of Rehabilitation. Remember - you can invite anyone to planning meetings who you think will be helpful to the process.

For the student who has finished high school with a certificate of completion (rather than a diploma), the school district can still provide vocational education and job opportunities until age 22 through the Workability program. Both you and your teen should discuss those options with the transition or Workability specialist who is on the IEP team (Workability is available to students with an IEP ages 16 to 22 years old).

Tri Counties California Regional Center has contracted with numerous programs in the community to provide vocational training and supervised ("sheltered") employment for consumers who are age 22 (or whose special education services have ended). Talk with your teen's service coordinator for more information about available programs.

Employment/Vocational Resources:

- Tri Counties Regional Center: (805) 962-7881 (800) 322-6994
- Department of Rehabilitation: Santa Barbara District, (805) 560-8130 (VOICE), (805) 560-8167 (TTY), 509 East Montecito Street, Suite 101, Santa Barbara, CA 93103-3216

Santa Maria Branch, (Santa Barbara District affiliate), (805) 928-1891, (Voice/TTY), 1775 S. McClelland Street, Santa Maria, CA 93454-7634

Adult Day Programs

Typically, an adult day program is vendored by Tri Counties Regional Center to serve its consumers. There are different types of programs that provide training in self-care, self-advocacy, community integration and employment. Some programs are site-based where consumers participate in activities on site. Others are either community based or a combination of the two.

There are different types of programs vendored that provide different levels of supervision and staffing ratios. If you think your teen would benefit from an adult day program, ask your Alta service coordinator for more information about what types of programs are available.

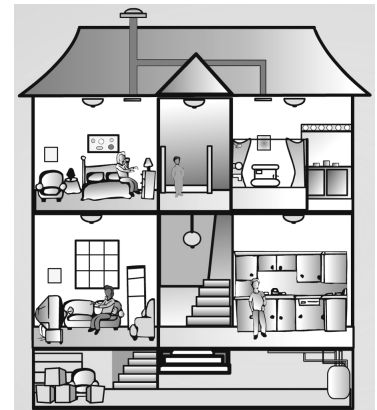
Moving Out - Independent Living or Group Homes

"I was so happy to learn that there are different options for living arrangements for my son when he is ready to move out on his own."

There are several options for living arrangements that might be available to your teen, depending upon his or her level of independence. Your teen's school district probably offers a program that teaches Independent Living Skills (ILS). Contact your teen's program specialist to discuss where the program(s) are offered and how it can be added to your teen's IEP. For those who no longer receive special education services, the Tri Counties Regional Center may also be able to provide an ILS program. Ask your service coordinator for more information.

Your teen may choose to live independently in an apartment or with roommates. If that is what your teen decides, encourage and support him/her. After all, you won't always be able to care for your child and the more independent he or she can become the better.

If your teen needs help and supervision, but still wants to live in his or her own home, Supported Living Services (SLS) provide services which support the adult consumer's efforts to do so. Several agencies which provide SLS are vendored by Tri Counties Regional Center. The individual pays for his or her own living expenses (for example, rent, utilities, food and entertainment) out of SSI, work earnings or other personal resources. The Regional Center pays the vendor to provide the supported living services.



"Supported Living Services (SLS) consist of a broad range of services to adults with developmental disabilities who, through the Individual Program Plan (IPP) process (through the Tri Counties Regional Center), choose to live in homes they themselves own or rent in the community. SLS may include assistance with selecting and moving into a home; choosing personal attendants and housemates; acquiring household furnishings; common daily living activities and emergencies; becoming a participating member in community life; managing personal financial affairs, as well as other supports.

(Supported living) services help individuals exercise meaningful choice and control in their daily lives, including where and with whom to live. SLS is designed to foster individuals' nurturing relationships, full membership in the community, and work toward their long-range personal goals. Because these may be life-long concerns, Supported Living Services are offered for as long and as often as needed, with the flexibility required to meet a person's changing needs over time, and without regard solely to the level of disability. Typically, a supported living service agency works with the individual to establish and maintain a safe, stable, and independent life in his or her own home. But it is also possible for some individuals to supervise their services themselves, to secure the maximum possible level of personal independence.

Individuals who choose to live in their own homes, and the agencies or other people who support them, often will need information about affordable housing options, sources of financial support such as Supplementary Security Income (SSI), and how to stretch a limited budget to meet living expenses. These are the ordinary challenges that are inseparable from a truly self-directed life in the community. For the many adults for whom SLS makes great sense, such challenges are often also road signs on the path to a satisfying life."

(From the California Department of Developmental Services website:
www.dds.ca.gov/livingarrang/sls.cfm)

Another option to be considered is a group home. Group homes offers a level of independence for the teen or young adult as they are no longer living under their parents' roof; however staff oversees schedules, routines, personal care and behavior. The drawbacks to the group home setting is that your teen may have to share a room, the environment will probably be fairly structured and may not be able to adhere to your teen's preferences and personal taste.

The following are some resources on housing, independent living, supported living, and group homes:

Tri Counties Regional Center

- Santa Barbara, Main Office, 520 East Montecito Street, Santa Barbara, CA 93103- 3278, (805) 962-7881 (800) 322-6994 FAX (805) 884-7229 Email www.tri-counties.org
- Santa Maria, 1234 Fairway Dr. Suite A, Santa Maria, CA 93455, (805) 922-4640 (800) 266-9071 FAX (805) 922-4350 www.tri-counties.org
- California Supported Living Network: www.supportedliving.com
- California Dept. of Developmental Services: www.dds.ca.gov/livingarrang/sls.cfm
- Independent Living Resource Center (ILRC): (805) 963-0595

Attendants & Supported Living Assistants

If your teen plans to live independently he or she may also require attendant(s) to assist with the tasks of daily living or assistant(s) to provide support and/or supervision. Even if a teen continues to live at home, he or she might also require help as parents grow older and less able to provide all necessary care. If your teen is a client of the Tri-Counties Regional Center your service coordinator may help guide you in the search to find attendant help.

Steps to follow when hiring a personal care attendant (PCA) or supported living assistant:
(Adapted from Kentucky Commission for Children with Special Health Care Needs - KY TEACH Project)

- Tasks - Identify the kind of support or assistance that will be needed.
- Payment - Determine how the services will be paid and how much can be budgeted.
- Job Description - Write a list of what assistance is needed. Be specific when describing a task. Develop a sample daily schedule that lists what tasks will be required, and when they should be done.
- Qualifications - Make a list of what kinds of training and work experience that the applicant should have, including such training as First Aid, CPR, etc. and keep in mind that the more qualified, the more the services will cost.
- Finding an applicant - You and your teen may consult your Tri-Counties service coordinator for information about vendorized supported living services agencies, which can then help find applicants. You can also contact Independent Living Resource Center (805) 963-0595, an employment agency, place an advertisement in a local newspaper, newsletter or on a bulletin board in order to find a PCA. List the minimum qualifications that you expect. You may also want to know what kind of transportation the candidate has. Provide a phone number, email address or post office box for responses. (For safety, do not include your home address.)
- Interview - Prepare a list of question before the interview. Tell the candidate specifically what assistance/supports your teen requires. Show the candidate the sample daily schedule. For safety, consider holding the interviews at some place other than your home. If the teen conducts the interview, have someone nearby such as a family member or friend.
- Before the interview, ask the applicant for the following information:
 - Legal name,
 - Address,
 - Phone number,
 - Social security number,
 - Drivers license number,
 - Date the person can begin working for you,



- Previous work experience, including name, address, and phone number of
- Education and training,
- Disclosure of previous felony convictions,
- Names and phone numbers of references,

After the PCA/assistant has been hired, it is important that he or she be trained. If you and your teen are working with a supported living agency, it can help with training. Clearly explain is expected and let the PCA know if there is personal information that is confidential. Encourage your teen to be assertive when communicating his or her needs, feelings and decisions.

Your teen and the PCA/assistant have the right to different feelings, opinions and points of view, but should always be respectful of each other. If there is a problem, help your teen to handle it promptly and in a professional manner. Clearly identify the problem and tell the PCA/assistant what you expect to happen, and then thank the PCA/assistant for listening. Give the PCA/assistant feedback - if the situation has improved, tell him/her. If you have made a reasonable request and clearly communicated it to the PCA/assistant and the problem continues, you may need to let the person go.

Backup Support - Maintain backup support in case the PCA /assistant calls in sick, suddenly quits or it becomes necessary to fire him/her.

The parent of the teen with special needs should allow him or her to take the lead in developing the job description and interviewing the PCA. Your teen must feel comfortable with the PCA because some of the tasks that he or she will perform might be very personal. While you can help to evaluate the choices, the decision should be up to the teen. This is an important step in developing self-advocacy, self-determination and other independent living skills.

Money and Benefits

Supplemental Security Income (SSI)

SSI is a monthly cash benefit program administered by the Social Security Administration. The State of California adds a State Supplemental Payment (SSP). It is not necessary to have paid into Social Security, but applicants must meet financial and medical eligibility criteria. Children who were not eligible under age 18 because the family income was too high may qualify on their own and should reapply after age 18. SSI recipients are automatically eligible for Medi-Cal.

A person can work and still get SSI unless his or her income gets so high that he or she is no longer financially eligible. SSI has generous income counting rules. One half of the earned income is not counted in figuring the amount of the SSI payment. A person can also reduce countable income and thus increase the amount of the SSI payment through Impairment Related Work Expense (IRWE) deductions. These are the charges the recipient pays out of pocket for assistance and treatment related to the disability and for the extra expenses someone has because of working and having a disability. For example, if a person lives in a board and care which provides care and supervision in addition room and board, the value of these services can be deducted from any earned income as an Impairment Related Work Expense.

SSI and PASS Plans

With a "Plan for Achieving Self Support" or PASS, income or an excess resource can be sheltered and not counted in determining eligibility for SSI. The income or resources sheltered can be used to pay for tuition, equipment needed to work, etc. Persons interested in seeing whether a PASS would assist them, and particularly persons not now eligible for SSI, should be referred to someone with expertise in writing and implementing Plans for Achieving Self Support.

Services:

- Medi-Cal
- Monthly cash benefit

Eligibility:

- Must be blind or have a physical or mental impairment resulting in marked and severe functional limitations and expected to last at least 12 months
- Have limited income (below \$500/month for a child) and limited resources (less than \$2,000)
- Meet citizenship and residence requirements

How to Apply: Call 800-772-1213 Web site: www.ssa.gov

Safety Skills

People with disabilities can be more vulnerable to abuse than other populations. As your teen spends less time with you and more time in the community you will want to be sure that he/she is prepared to deal with people who may be unscrupulous. Your SELPA or Tri Counties Regional Center may offer a program to help with safety skills.

Basic safety skills:

- Teach your teen not to be alone in an isolated place and what to do if someone is following him or her.
- Teach your teen about inappropriate touching or actions and who to tell.
- Consider purchasing a self defense device for your teen, such as a personal alarm or whistle.
- Teach your teen to only take safe routes to and from busses or stores.
- Teach your teen about the buddy system.
- Make sure he or she knows how to call for help (In most counties, if you call 911 on a cell phone you get the Highway Patrol and may be put on hold. Consider programming your teen's cell phone with your local police department emergency number.)
- Teach your teen that it is okay to question someone who is in an authority position if he/she does not feel right about being told to do something.
- Purchase a Medic Alert (888-633-4298) bracelet and teach your teen that the phone number on the bracelet can be called for help if he or she is ever lost. (Medic Alert bracelets can be purchased for people who have cognitive needs in addition to those who have medical needs.)

Friends & Relationships



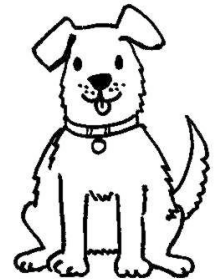
Just because your teen has a disability doesn't mean he/she won't be interested in having a boyfriend or girlfriend. It may mean, however, that you have to be more vigilant in communicating with your child what is appropriate social behavior and what isn't. It may also mean that you may be involved in facilitating dates by providing transportation, attendant services etc. depending on your teen's capabilities. Relationships are an important part of life - help your teen to maintain contact with friends he/she has made in school. Find new social activities that your teen may enjoy. There are also many community recreation programs for adults with developmental disabilities, as well as travel opportunities for persons with disabilities. Your SELPA or Tri Counties may offer a program to help with social/recreational skills or may be able to refer to other resources.

Social/Recreational Programs and other Resources in Santa Barbara County:

PARENT-TO-PARENT SUPPORT, Sponsored by Special Needs Network. Meets third Thursday of every month, 9:00 am at Cafe Monet, 1555 S. Broadway in Santa Maria. Contact: Diana (805) 937-8756 or JoAnne (805) 937-2465.

UCSB ADAPTED RECREATION PROGRAM, UCSB offers programs in handcycling, eye'm cycling, power soccer team practices, kayaking & more. Beach wheelchairs are available and so are scholarships. Contact: Rick Van Hoorn (805) 448.6740 or email Rick.Vanhoorn@essr.ucsb.edu.

CITY OF SANTA BARBARA PARKS & RECREATION DEPARTMENT, Check out what they have to offer. Contact: Adapted Programs (805) 564.5421.



JR. WHEELCHAIR SPORTS CAMP Ages 5 - 19 who use a wheelchair to participate in sports. Contact Rene' Vanhoorn: 805.569.8999 (run through Cottage Hospital Rehab).

FAMILY FIRST, A family resource center and parent network. Provides parent-to-parent and family support, parent/professional collaboration, resource meetings and workshop information and referrals. Contact: North County (805) 347-2775 / South County (805) 683-2145.

SOMETHING FOR THE SIBLINGS, The Special Needs Network is a new club for the siblings of individuals with disabilities. The club will consist of several fun activities and will be a chance to get away and relax with others who also have siblings with disabilities. Contact: Laura King, (805) 344-1403.

THIRD FRIDAY, Join members of your Family First team of parents who have children with special needs every third Friday of the month from 9:00 am - 11:00 am, Alpha Resource Connections Library. Location: Tri-Counties Regional Center, 520 E. Montecito St, Santa Barbara. Contact Patti: (805) 683-2145.

SANTA MARIA SPECIAL EDUCATION & SUPPORT INFORMATION, Kathy Rowley has started a

Conservatorship is a legal proceeding in which an individual or agency (to be known as the "conservator") is appointed by a court to be responsible for a person who needs assistance in activities of daily living (the "conservatee"). A **conservator of the person** must ensure that the conservatee is properly fed, clothed and housed. A **conservator of the estate** is responsible for managing the conservatee's money and other property. One individual may serve as either conservator of the person or conservator of the estate or both. Conservatorship applies to an adult, i.e., a person eighteen (18) years of age or older.

Before the court will grant a petition for the appointment of a personal conservator, it must be shown that the proposed conservatee is unable to provide properly for his or her personal needs for physical health, food, clothing or shelter. A conservator of the estate may be appointed for a person who is substantially unable to manage his or her own financial resources, or to resist fraud or undue influence.

What Is Limited Conservatorship?

Limited conservatorship is a form of general conservatorship and applies only to adults who are "developmentally disabled" as defined in state law, and who are, or could be, clients of California's regional centers serving developmentally disabled citizens. This protective legal arrangement is "limited" because the adult with developmental disabilities retains the power to care for himself or herself and/or to manage his or her financial resources commensurate with his or her ability to do so, as determined by the court. A limited conservatorship is used to promote and protect the well being of the individual and is designed to encourage the development of maximum self-reliance and independence.

Why Is Conservatorship Important?

If you are the parent of an adult child who is developmentally disabled, conservatorship may provide you with the authority to speak on behalf of your son or daughter, or to play a role in his or her care, which you would not otherwise have.

As the parent of a minor child, you are the natural guardian and possess generally the same powers and authority as a court-appointed guardian. When your child reaches the age of majority, he or she becomes emancipated from parental control. The law presumes that the individual, regardless of handicapping condition, is capable of exercising the rights of an adult.

When a developmental or mental impairment limits an adult's capacity to exercise his or her rights, the person may need someone else to exercise certain rights on his or her behalf. Conservatorship would enable the parent to act on behalf of the person subject to periodic reviews by the court.

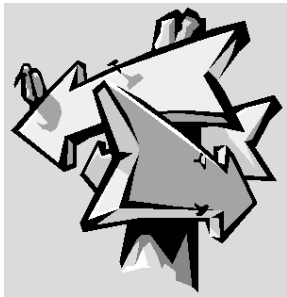
Conservatorship is most important when consent is required for a particular act, and a person with mental retardation or other developmental disability is unable to give it. For example, the "informed consent" of a patient is required before an operation can be performed. If the patient is a minor with mental retardation or other developmental disability, physicians and hospitals will generally accept the consent of the parent. If the patient is an adult with mental retardation or other developmental disability, parental consent frequently is not accepted



unless the parent is also the patient's conservator. Without requesting a conservatorship, a parent may petition a court for authorization to give consent to medical treatment. Additionally, in some situations, the director of a regional center may consent to medical treatment for a regional center client.

The powers and duties of the conservator will be set forth in the order of appointment and statutory law. A clear understanding of the effect of these powers and duties is important when dealing with public agencies and managers of residential and day programs. For instance, the parent conservator may have to be notified of and approve proposed changes in residence, education or habilitation services.

How Can I Determine If a Conservatorship Is Necessary?



The decision whether or not to seek conservatorship will depend on the facts of your individual case, and you should seek the advice of counsel. Some questions you should ask to determine whether a conservatorship is necessary are:

1. What decisions affecting the financial well being of the individual with developmental disabilities is he or she *unable* to make? Can these decisions be made effectively through means other than the creation of a conservatorship? For example, if the individual's income is limited to SSI, money management may be accomplished through a representative payee.
2. Is the adult who is mentally retarded or developmentally disabled able to provide properly for his or her own personal needs for physical health, food, clothing or shelter?
3. Will a family doctor continue to accept parental consent for medical treatment for a child who is mentally retarded or developmentally disabled, even though that child is an adult?
4. Does the regional center serving the developmentally disabled person recommend conservatorship?

How Is Conservatorship Established?

The conservatorship proceeding begins by filing a petition with the proper court, usually the Superior Court of the county in which the proposed conservatee resides. Notices of hearing and a copy of the petition must be mailed to certain persons and agencies at least 15 days before the hearing and a document, known as a citation, must be personally presented to the proposed conservatee.

The proposed conservatee must attend the hearing unless he or she is (1) out of the state when served, (2) certified as medically unable to do so or, (3) unwilling to attend and does not oppose the petition. Whether or not the proposed conservatee attends the hearing, a court investigator must interview the proposed conservatee and, among other things, inform him or her of the nature of the proceedings and determine whether the individual is able to attend the hearing, wishes to contest the conservatorship, objects to the proposed conservator, or wishes to be represented by legal counsel. This requirement of an investigation and report does not apply if the

proposed conservatee will attend the hearing and is the person who executed the petition for conservatorship or who nominated his or her own conservator.

Once established, a probate conservatorship need not be renewed but continues until the death of the conservatee or until otherwise terminated by order of the court. The death of a limited conservator terminates the relationship of limited conservator/limited conservatee. To fill the vacancy, a petition for appointment of a successor limited conservator must be filed.

Within 90 days after appointment, all conservators must file with the court and the court investigator a general plan detailing how the personal and financial needs of the conservatee will be met. Notice of the filing of the plan must be given to all those who received notice of the original petition. The court has the option of scheduling a hearing if it determines that the plan is not in the best interests of the conservatee or if it receives objections to the plan within 30 days after mailing the notice of filing.

If the conservatorship includes estate management, an accounting must be filed with the court at the end of the first year after appointment and every two years thereafter. Whether or not an accounting is required, the court investigator must interview the conservatee again on or about the anniversary of the establishment of the conservatorship and every other year thereafter. The purpose of the interview is essentially to determine whether the conservatorship continues to be necessary and whether the conservator is acting in the best interests of the conservatee. The investigator's report is forwarded to the court with a copy to the conservator or to his or her attorney. The investigator may visit persons other than the conservatee to determine whether the conservator is acting in the conservatee's best interests. Conservatees are charged the cost to the county of the initial investigation and all subsequent periodic investigations. However, if the conservatee does not have sufficient funds to pay this cost, or if it would pose a hardship, the court will waive this charge.

Who May Act as Conservator?

Any individual who is an adult may be a conservator if the court is convinced that the person would act in the best interests of the conservatee. Private professional conservators may also serve in this capacity, as long as they file a background statement annually about the person(s) who perform the conservatorship services.

Two or more persons may serve as joint conservators. Because a majority of the conservators must join in any action, it is often cumbersome to have more than two conservators. The advantage of having more than one conservator is that, if one should die, the other may continue to act without the necessity of filing another petition for the appointment of a new conservator.

At What Point Should I Consider Conservatorship?



Parents may wish to seek the advice of an attorney regarding conservatorship on two occasions: (1) when the child who is mentally retarded or developmentally disabled has reached (or is nearing) 18 years of age, and (2) when the parents are writing their wills.

Conservatorship planning as a child reaches the age of 18 is important for the reasons already discussed. When drafting wills, one should consider conservatorship in the event that the person who is disabled will require supervision after the parents have died. If so, the will may be used to nominate a conservator to be appointed upon the death of both parents.

Though the nomination is not legally binding, courts will make every effort to honor it unless convinced that conservatorship is unnecessary or that the person nominated would not act in the best interests of the proposed conservatee.

How Do I Find an Attorney Knowledgeable in this Field?

Contact your local Association for Retarded Citizens (ARC). Most associations are familiar with the attorneys in their area who have had experience in advising parents with children who are mentally retarded or developmentally disabled. If you are still unsuccessful, many municipal and county bar associations have a lawyer referral panel.

LIMITED CONSERVATORSHIP

What Powers Are Limited? Like a general conservator, a limited conservator has the care, custody and control of the limited conservatee except that, **unless specifically requested** in the petition and granted in the court's order, a limited conservator **does not have** any of the following powers or controls:

1. To determine the limited conservatee's place of residence;
2. To have access to the limited conservatee's confidential records;
3. To control the limited conservatee's right to marry;
4. To control the limited conservatee's right to contract;
5. To give consent for the limited conservatee's medical treatment;
6. To control the limited conservatee's social and sexual contacts and relations;

7. To make decisions concerning the limited conservatee's education.

However, each limited conservator is required to secure for the limited conservatee such habilitation or treatment, training, education, medical and psychological services, and social and vocational opportunity as appropriate and as will assist the limited conservatee in the development of maximum self-reliance and independence.

Any time a conservatorship petition alleges that the proposed conservatee lacks the capacity to give informed consent to medical treatment and asks that the court give the proposed conservator exclusive power in that domain, the petition must be accompanied by a medical doctor's declaration which states that the proposed conservatee lacks the capacity to give informed consent to any form of medical treatment. In addition, a limited conservator of the estate has authority to manage only those assets of the limited conservatee which are listed in the order of appointment.

What Role Does the Regional Center Play in Limited Conservatorships?

In every conservatorship involving a person who is developmentally disabled (subject to the consent of the proposed limited conservatee) the appropriate regional center must perform an assessment of the proposed conservatee and submit a report to the court. The report must specify the nature and degree of the proposed conservatee's disability and the areas in which the proposed conservatee may need assistance. The costs of these assessments will be borne by the regional center. At least five days before the hearing, a copy of the regional center's report must also be sent to the proposed conservatee and to the petitioner and/or to any attorneys representing the parties.

May a General Conservator, Rather than a Limited Conservator, Be Appointed for a Person Who Is Developmentally Disabled?

If the cause of the incapacity requiring conservatorship involves a developmental disability, the petitioner must file a petition for a limited conservatorship. At the hearing on that petition, if the court finds that the proposed conservatee lacks the capacity to perform all of the tasks necessary to provide properly for his or her own personal needs for physical health, food, clothing, or shelter, the court has the authority to establish either a limited or a general conservatorship.

GENERAL CONSERVATORSHIP

1. Consent to Treatment -- Since January 1, 1981, a conservator does not have the power to consent to medical treatment on behalf of the conservatee unless a court order is obtained which authorizes substituted consent. The only exception to this rule is that consent may be given without a court order if the conservatee **does not object** to the proposed treatment.

The order authorizing substituted consent may be one which finds the conservatee incapable of giving consent to any form of treatment and transfers the sole power of consent to the conservator. Such an order need be obtained only once since it applies to all forms of permitted treatment. If the conservatee is capable of consenting to some forms of treatment but not others, then the conservator must wait until treatment is required and obtain an order relating to the

specific form of treatment proposed.

Under the Due Process Incompetence Determinations Act, effective in 1996, a person has the capacity to give informed consent to medical treatment if the person is able to do all of the following:

- (a) Respond knowingly and intelligently to questions about medical treatment.
- (b) Understand the nature and seriousness of the illness that the person has.
- (c) Understand the nature of the medical treatment that is being recommended by the health care provider.
- (d) Understand the probable degree and duration of any benefits and risks of the medical treatment that is being recommended and the consequences of lack of treatment.
- (e) Understand the nature, risks and benefits of any reasonable alternatives.

Of course no conservator may give consent to treatment which would be harmful to the conservatee. Also, the law **prohibits** either a conservator or a court from authorizing electro-shock therapy, psycho surgery, or the administration of certain experimental drugs. Sterilization may occur in the context of a limited conservatorship but only under certain narrow circumstances. Sterilization cannot occur in any instance where it is determined that the individual knowingly opposes sterilization. Even absent this opposition, for a sterilization to occur, a special procedure must be followed which involves many protections for the limited conservatee. These protections include: mandatory appointment of counsel for the limited conservatee, appointment of a "facilitator" to assist the limited conservatee, assembly of a special panel of experts to personally interview the limited conservatee and make a recommendation to the court, and investigation by the appropriate regional center.

2. Contractual Capacity -- Since January 1, 1981, a conservatee cannot enter into contracts or other financial transactions in excess of necessary expenses for food and clothing. The only way a competent conservatee may retain the right to enter into contracts is to obtain an order from the Superior Court. The procedure for obtaining such an order is set out in the 1981 statute.

If you need to establish conservatorship for someone who will soon be 18, it is a good idea to start the process more than 3 months before the person's 18th birthday. However, you do not have to establish conservatorship of your child with a disability when he or she becomes an adult if you do not want to. If you change your mind, you can apply for conservatorship at a later time.

It is good idea to talk to an experienced lawyer or to ask a lawyer to review your forms for conservatorship if you decide to fill them out yourself, but you may also get help from www.courtinfo.ca.gov/selfhelp/seniors/duties.htm. You can also download a copy of "Handbook for Conservators", published by the Judicial Council of California at www.courtinfo.ca.gov/selfhelp/seniors/handbook.htm or call 916-875-3400 to find out where to purchase a copy locally.

In order to establish conservatorship you or your lawyer must file court forms usually in the county where the adult with the disability lives. The person who files is called the petitioner. You can download the forms at www.courtinfo.ca.gov/forms. There may also be local forms you must fill out. Check with the Superior Court of California, County of Sacramento Probate Office (916-875-3400).

If you or the proposed conservatee cannot afford to pay the court fees, you can apply to have the fees waived.

Power of Attorney

An alternative to conservatorship may be for the teen to execute durable power of attorney and name a parent or other responsible adult as the agent. Obtaining durable power of attorney should be discussed with an experienced lawyer to determine if it is an appropriate option, since the person must be considered "competent" in order to execute the request.

For more information, contact:

- Protection & Advocacy: 1-800-776-5746
"Conservatorship, Trusts & Wills for People with Developmental or Other Disabilities - A Guide for Families" available at www.pai.ca.org/pubs/500501.pdf
- Independent Living Resource Center: (805) 963-0595

Estate Planning

Special Needs Trust

When you have a teen or young adult with a disability, estate planning can be quite tricky. If you haven't begun to plan already, you might think about doing so as soon as possible. Because many adult children with developmental disabilities will rely on public benefits for medical and living expenses, it is important to protect these assets. A special needs trust allows a person with developmental disabilities to inherit money or assets without jeopardizing those benefits. Parents leave resources to the trust which is then managed by a trustee on behalf of the adult child. Even if you don't think you have enough assets now to set up a special needs trust, consider talking with an estate planning attorney about possible options, including how other people such as grandparents, aunts or uncles may also leave gifts to the special needs trust for your teen or adult child.

A helpful resource is: "Conservatorship, Trusts & Wills for People with Developmental or Other Disabilities - A Guide for Families" available at www.pai.ca.org/pubs/500501.pdf or call Protection and Advocacy at 1-800-776-5746.

Adapting Your Home for an Adult with a Disability

Your teen may already have outgrown you, in size and weight. If he or she plans on continuing to live at home as an adult and has mobility issues, you should start early to plan for what type of assistance and adaptive equipment your teen will need as an adult, especially if he or she is currently a client of California Children's Services (CCS) since CCS covers children only up until age 21.

Voter Registration

"My son just voted for the first time, even though he has cerebral palsy. He took the process very seriously and is so proud of his knowledge of the issues!"

Anyone, including people with a disability can vote as long as he or she meets certain conditions. The person must:

- Be a United States citizen,
- Live in California,
- Be at least 18 years old,
- Not be in prison or on parole for a felony,
- Not have been told by a court that he or she cannot register to vote.



To register to vote, a person can obtain a voter registration card from the Secretary of State's office (800-345-VOTE or online at: www.ss.ca.gov/elections/elections_vr.htm), Santa Barbara County Voter Registration Absentee Voting (805) 568-222 or online at: www.elections.saccounty.net/), Tri-Counties Regional Center, Protection and Advocacy, Inc. (PAI).

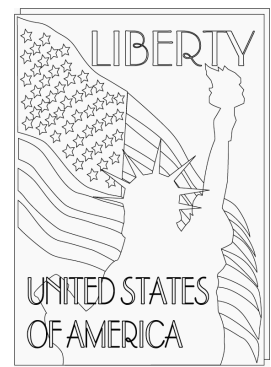
Selective Service Registration

All male U.S. citizens born after December 31, 1959, who are 18 but not yet 26 years old, including those who are "handicapped physically or mentally and able to function in public with or without assistance" must register for selective service. Among those not required to register are those who are "handicapped physically or mentally and who are continually confined to a residence, hospital or institution."

The easiest and fastest way for a man to register is to register on-line. A young man can also fill out a registration card and send it to the Selective Service System.

Here are some places to register:

- On-line with Selective Service at www.sss.gov
- At The Post Office - Fill out the Selective Service registration forms available at any U.S. Post Office.
- By Mail-Mailback® cards are available at some post offices. A man can fill out the card at home and mail it directly to: Selective Service System, Registration Information Office, P.O. Box 94638, Palatine, IL 60094-4638.
- At High School - More than half of all high schools have a staff member or teacher appointed as a Selective Service Registrar. These individuals help register male high school students.



Department of Motor Vehicles

Disabled Parking Placard

A person can be certified disabled by a physician if he or she has limited mobility or one of the following conditions:

- Heart or circulatory disease,
- Lung disease,
- A disease or disorder that significantly limits the use of lower extremities,
- Specific visual problems, including low vision, partial-sightedness, or blindness,
- The loss, or loss of the use, of one or both lower extremities or both hands.

Disabled *license plates* are available only to those with permanent disabilities. There is no fee for the plates other than the normal annual vehicle registration fee.

Both permanent and temporary disabled parking placards require a doctor's certification unless the person has lost a lower extremity or both hands, and goes in person to the local DMV office to obtain a placard or already has a California disabled person (DP) or disabled veteran (DV) license plates.



To Apply for a Disabled Placard or License Plate:

- Download and print a copy of the "Application for Disabled Person Placard or Plates" form from www.dmv.ca.gov/forms/reg/regl95.pdf,

- Have a doctor sign the disability certification,
- Mail the completed application to the address indicated on the form.

For a temporary placard, include a \$6 fee. Permanent placards and license plates are free,

- Or, make an appointment at a local DMV office to deliver the application in person.

The placard or plates will be received within three weeks after the DMV receives the application.

Renewals:

Placards for permanently disabled persons are automatically renewed by the DMV.

Parking privileges for DP placard, DP plates or DV plates:

- In parking spaces with the International Symbol of Access (wheelchair symbol),
- Next to a blue curb authorized for handicap parking,
- Next to a green curb for as long as you wish,
- In an on-street metered parking space at no charge,
- In an area that indicates it requires a resident or merchant permit,

In addition to parking privileges, service stations must refuel a disabled person's vehicle at self-service rates unless the service facility has only one employee on duty.

Drivers License



People who have special needs frequently can obtain a drivers license. Under the Americans with Disabilities Act (ADA),

drivers training companies must make "reasonable accommodations" to people with disabilities. After drivers training, the person must also pass both a drivers test and a written (with accommodations, as necessary) test with the Department of Motor Vehicles (DMV). Check local phone books to find drivers training programs in the area.

The Association for Driver Rehabilitation Specialists (ADED) supports professionals working in the field of driver education/driver training and transportation equipment modifications for persons with disabilities. The ADED is the primary professional organization in this specialized area and it supports and encourages equipment development to maximize the transportation options for persons with disabilities.

Contact:

To locate a professional in your area, call 800-290-2344

Website: www.driver-ed.org

California Identification (ID) Card

DMV issues ID cards to persons of any age. The ID card looks like a driver license, but is used for identification purposes only. A regular ID card is valid for six years, and a senior citizen ID card is valid for 10 years. To qualify for a senior citizen ID card, the person must be age 62 or older.

To apply for an ID card:

- Visit a DMV office (make an appointment for faster service) and complete an application form. (An original form must be submitted. Copies will not be accepted.),
- Give a thumb print,
- Have a picture taken,
- Provide a social security number. (It will be verified with the Social Security Administration),
- Verify birth date with birth certificate,
- Pay the application fee. (No fee for a senior citizen ID card.)

Verify the address on the application before leaving DMV and tell the DMV representative if the address is incorrect. The new ID will be mailed within 60 days. If the card has not been received after 60 days, call 800-777-0133 to check the status. Have the receipt and/or old ID card available to provide information when requested.

DMV will exchange a valid license for a no-fee ID card to drivers who are no longer able to drive safely because of a physical or mental condition. Please call the local DMV for additional information.

To renew an ID card:

- Visit a DMV office (make an appointment for faster service) and complete an application form. (An original form must be submitted. Copies will not be accepted.),
- Give a thumb print,
- Have a picture taken,

- Provide a social security number. (It will be verified with the Social Security Administration),
- Verify birth date with birth certificate,
- Pay the application fee. (No fee for a senior citizen ID card.)

Verify the address on the application before leaving DMV and tell the DMV representative if the address is incorrect. The new ID will be mailed within 60 days. If the card has not been received after 60 days, call 800-777-0133 to check the status. Have the receipt and/or old ID card available to provide information when requested.

South Santa Barbara County - Public Transportation

Metropolitan Transit District (MTD) (805) 683-3702

Private Transportation - demand response door-to-door transportation; schedule ride, complaints
HELP of Carpinteria (Carpinteria only, no access for wheelchair users). (805) 684-0065

Dial-a-Ride - para-transit; demand response door-to-door transportation, information, schedule rides, complaints
Easy Lift Transportation (805) 681-1181

North Santa Barbara County - Public Transportation

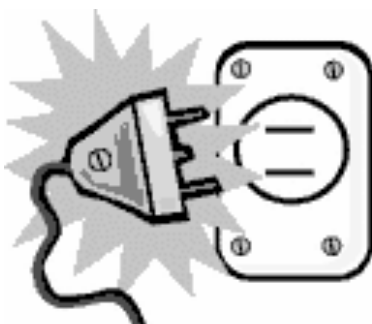
Santa Maria Area Transit (SMAT) (805) 928-5624

Dial-a-Ride - para-transit, demand response door-to-door transportation, information, schedule rides, complaints.

Lompoc Transit, City of (COLT) (805) 736-6666
Santa Maria Organization of Transportation Helpers (SMOOTH) (805) 922-8476
Santa Ynez Valley Transit (805) 688-4718

Utilities

Both Southern California Edison (electrical service) and Southern California Gas Co. (gas) may have discounted rates for people with special healthcare needs who meet their requirements.



SMUD

If a full-time resident of the household requires an electrically powered device for medical reasons, SMUD's Medical Equipment Discount (MED) Rate can save more than 30 percent on the electric bill every month.

A medical equipment device, for purposes of MED Rate, is defined as any medical device requiring utility-supplied energy for its operation that is regularly required to sustain the life of a full-time resident in the

home.

Qualifying medical equipment devices include, but are not limited to:

- Respirators
- Iron lungs
- Hemodialysis machines
- Suction machines

- Electric nerve stimulators
- Pressure pads and pumps
- Electrostatic and ultrasonic nebulizers, compressors, IPPB machines
- Motorized wheelchairs

The term "medical equipment" also includes air conditioning or electric heat for paraplegic, hemiplegic, or quadriplegic and multiple sclerosis patients.

To qualify, the customer must provide certification by a physician or osteopath that a full-time resident in the home is:

- Dependent on a medical equipment device used in the home, or
- Paraplegic, hemiplegic or quadriplegic, or a multiple sclerosis patient with special electric space-heating needs or air conditioning needs. Medical conditions other than paraplegia, hemiplegia, quadriplegia or multiple sclerosis may also qualify for this rate if electrically operated equipment is used to sustain, restore or supplant a vital function.

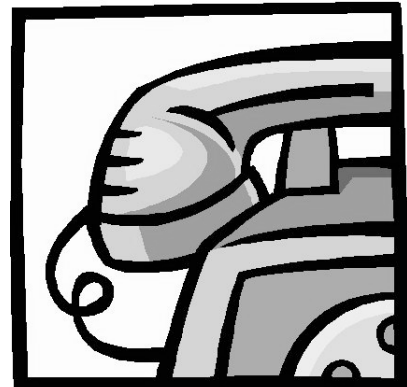
To print out the application, go to:
www.smud.org/residential/pdf/MEb_rate.pdf or call 888-742-SMUD (7683)

California Telephone Access Program

Provides equipment and/or service free of charge to people with special needs to help them use telephone services more effectively.

Services/Equipment:

- Speed dial
- Three way calling
- Operator assisted dialing
- Directory assistance exemption
- Amplifiers
- Braille TTYs
- Headsets
- Ring signal devices
- Switches
- Special telephones
- TTYs
- Accessories



Eligibility:

To be eligible, a person must:

- Live in California
- Have telephone service at residence
- Be certified in one or more of the following disabilities - either temporarily or permanently:
 - Deaf/deafened
 - Hard of hearing
 - Cognitive disability
 - Mobility problems
 - Blind/low vision
 - Speech difficulty

To Apply: Complete application form that is available from call center at 800-806-1191
Website: <http://www.ddtp.org/DDTP/>

Agencies & Groups Helpful For Parents of Teens with Special Needs

Advocacy/Family Support

- * *Area Board IX* (Advocates on behalf of people w/ disabilities in California.)
<http://www.areaboard9.org/> 805-685-8395

- * *The ARC* (Nat'l organization of and for people w/ mental retardation & related disabilities.)
www.thearc.org 800-433-5255

- * *Beach Center of Families & Disability* (Works to enhance the quality of life of families, their partnerships with professionals, the support they receive during early childhood years, and their transition to adulthood to increase great expectations for the future.)
www.beachcenter.org 785-864-7600

- * *California Association of Family Empowerment Centers* (Provide information, resources, technical assistance, and systems change advocacy for a statewide network of local FECs which provide family education, empowerment, and parent-professional collaborative activities for families of children with disabilities ages 3-22 years old.) www.cafec.org

- * *Capitol People First Self-Advocates Training Self-Advocates* "We are people first, our disability is second!"
www.peoplefirstca.org
916- 552-6625

- * *Disability Rights Education & Defense Fund (DREDF)* (The mission is to advance the civil and human rights of people with disabilities through legal advocacy, training, education, and public policy and legislative development.)
www.dredf.org 800-348-4232 / 510-644-2555

- * *Family Village* (Web site for children and adults w/ disabilities and their families, and their friends and allies.)
www.familyvillage.wisc.edu

- * *Family Voices of California* (Grass roots family advocacy group focusing on health care related issues.)
www.familyvoicesca.org 888-835-5669

- * *Kentucky Cabinet for Health Services Commission for Children with Special Health Care Needs* (Information on youth transition to adulthood.) www.chfs.ky.gov/ccshcn/ccshcntransition.htm

- * *Make-A-Wish Foundation* (Grants wishes to children w/ life threatening medical conditions)
www.wish.org

- * *Matrix* (Parent Training & Information Ctr.)
www.matrixparents.org 707-586-3314

- * *Mothers United for Moral Support (MUMS)* (Nat'l parent match organization)
www.netnet.net/mums/ 877-336-5333
- * *National Information Ctr. For Children & Youth w/ Disabilities (NICHCY)* (Information on disabilities in infants, toddlers, children, and youth, IDEA, No Child Left Behind (as it relates to children with disabilities), and more.)
www.nichcy.org 800-695-0285
- * *Resource Foundation for Children with Challenges* (Provides educational resources & emotional support to families of children, adolescents, and young adults w/ disabilities.)
www.specialchild.com/RFCC/about.html
- * *Sibling Support Project* (Dedicated to the life-long concerns of brothers and sisters of people who have special needs.)
www.siblingsupport.org 206-297-6368
- * *University of Minnesota Nat'l Ctr. on Secondary Education & Training* (Information on transition to adult life. Parent briefs are clear & concise.)
www.ncset.org 612-624-2097
- * *University of Washington Adolescent Health Transition Program* (Information for adolescents to learn to manage their own health care.)
www.depts.washington.edu/healthtr/ 206-685-1358
- * *WarmLine Family Resource Center* (Support and resources for families of children w/ special needs)
www.warmlinefrc.org
 Sacramento: 916-922-9276 / 800-660-7995 Roseville: 916-782-7147

Health Services

- * *California Children's Services* (Health care for children who qualify and who have an eligible diagnosis)
www.dhs.ca.gov/org/pcf/cms/ccs
- * *My Friends Pediatric Day Healthcare Center* (Respite care for medically fragile children up to age 21.)
www.myfriendsonline.org

Developmental Disabilities

- * *Tri Counties Regional Center (TCRC)* (Serves individuals with developmental disabilities and their families.) www.tri-counties.org
- * *California Department of Developmental Services (DDS)* www.dds.cahwnet.gov
 916-654-1690 / 800-515-2229
- * *California Services for Technical Assistance and Training (CalSTAT)* (Supports and develops partnerships with schools and families by providing training, technical assistance and resources to both special education and general education. www.calstat.org)

* *Easter Seals* (Provides developmental services, employment training, adult day programs and warm water therapy) www.superiorca.easter-seals.org 916-485-6711

Education

* *California Department of Education, Special Education Division* (State agency which oversees both general and special education programs)
www.dds.ca.gov/spbranch/sed/ 916-319-0800

Diagnosis/Disability Specific

* *Alliance of Genetic Support Groups* (Contact information for groups that are involved with genetic diagnoses.) www.geneticalliance.org
202-966-5557

* *Canadian Adult Congenital Heart Network* (Provides comprehensive care and information to adult patients with congenital heart disease and their care providers.)
www.cachnet.org/

* *Families for Early Autism Treatment (FEAT)* (Non-profit organization providing education, advocacy and support for the Northern California autism community)
www.feat.org 916-463-5323

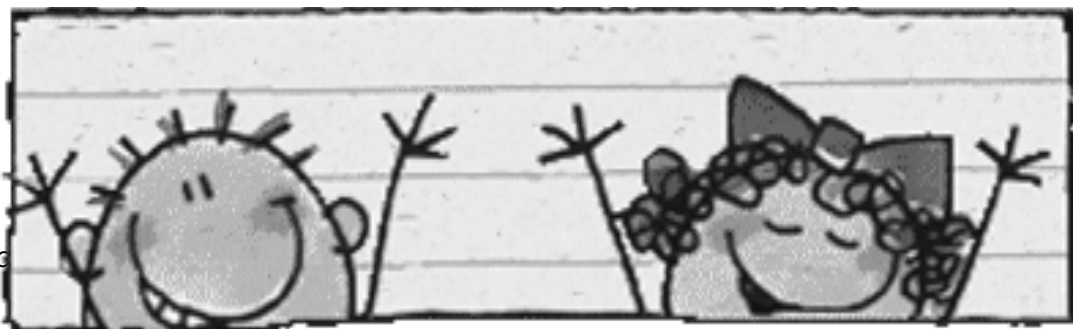
* *MIND Institute (UC Davis)* (An international, multidisciplinary research organization which strives to understand the causes and develop better treatments and ultimately cures for neurodevelopmental disorders.)
www.mindinstitute.org 888-883-0961

* *National Down Syndrome Society* (Works to people with Down syndrome and their families through national leadership in education, research and advocacy.)
www.ndss.org 800-221-4602

* *National Organization for Rare Disorders (NORD)* (Serves as the primary non-governmental clearinghouse for information on rare disorders. NORD also provides referrals support groups and other sources of assistance. www.rarediseases.org 800-999-6673

* *United Cerebral Palsy, Sacramento* (Provides programs and services that improve the independence, productivity, and quality of life of people with developmental disabilities and their families. www.ucpsacto.org 916-565-7700

* *California Brain Injury Assn.* (Provides information about Acquired Brain Injuries ABI or TBI)
2658 Mt. Vernon Ave.
Bakersfield, CA 93306-2924 ww.calbia.org



IPP MEETING PLANNER

This worksheet helps you plan for the services you want from the Regional Center. Use it to help you think about what you need to do things more independently.

A PLACE TO LIVE

Where do you live now?

- My own place
- A group home
- My own place with roommates
- A large care facility
- My parent's place

Other _____

Where do you want to live?

- Stay where I am
- My parent's place
- My own place
- A group home
- My own place with roommates
- A large care facility

Other _____

What services do you need to help you live where you want?

- More training
- More money
- An attendant or roommate
- Help finding a place to live
- Someone to give me regular support and help

Other _____

A PLACE TO WORK

Where do you work now?

- In the community without extra help
- In the community with an aid or job coach
- In a workshop or center
- I go to school
- I don't work or go to school

Other _____

Where do you want to work?

- In the community
- In a workshop or center
- I want to go to school
- I don't want to work

What kind of work do you want to do? _____

Other _____

What services do you need to help you work?

- A job coach or aide at the job
- Training in a workshop
- Other training
- More education
- Access to work place - ramps, etc.
- Transportation

Other _____

What type of medical care do you need?

- Doctor services
- Counseling
- Dentist services
- Sex education (safe sex; birth control)

Other _____

FUN AND LEISURE

What do you do for fun or with your free time?

- Visit friends
- Read

- Shop
- Take classes
- Go to movies or plays
- Volunteer work
- Play sports
- Listen to music
- Hobby
- Dating
- Watch TV

Other _____

What new things do you want to do?

- | | |
|--|--|
| <input type="checkbox"/> Visit friends | <input type="checkbox"/> Play sports |
| <input type="checkbox"/> Read | <input type="checkbox"/> Listen to music |
| <input type="checkbox"/> Shop | <input type="checkbox"/> Hobby |
| <input type="checkbox"/> Take classes | <input type="checkbox"/> Dating |
| <input type="checkbox"/> Go to movies or plays | <input type="checkbox"/> Watch TV |
| <input type="checkbox"/> Volunteer work | |

Other _____

What services do you need to help you do the things you want to do?

- Training
- Attendant
- Facilitator
- Transportation
- Set up a circle of friends
- Job Coach

Other _____

OTHER THINGS

What other things do you think you need help with?

- Cooking for myself
- Shopping for things I need
- Personal Care (For example: IHSS)
- Cleaning my place
- Managing my money

- Getting medical care
- Meeting more people/making friends
- Riding the bus or other transportation
- Learning about personal relationships
- Learning about sexual relationships/safe sex
- Getting along better with people
- Self advocacy and knowing my legal rights
- Problems with Social Security, SSI, or other assistance programs
- Learning about self-defense

Other _____

What other services do you need to help with these things?

- An attendant
- An assistant to help with chores
- Just someone to ask questions to
- Help setting up a circle of friends
- An advocate or lawyer
- A service coordinator to help me plan for and get services I need

Training (What type? _____)

Other _____

From "Your IPP, It's Not Just a Piece of Paper! A Self-Advocacy Manual for People Who Get
Services from Regional Centers"

Capitol People First & Protection and Advocacy, Inc. Peer Advocacy Project 1994

Revised 1998, 2003 www.pai-ca.org/PUBS/503801.pdf

Frequently Called Numbers/Support Network

