Part Three: Information Briefs

Connections for Information and Resources on Community Living (CIRCL)

April, 2001
Supported Living Services
Training Tool Box

General Information
for SLS Staff

Developed for

Connections for Information and Resources
on Community Living (CIRCL)
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through a contract with the
Department of Developmental Services

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Part Three: Information Briefs

Introduction

The material in Part Three was excerpted and adapted primarily from:

**Year 1, Direct Support Professional Training Resource Guide (1999).** Developed by the Department of Education and the Regional Occupational Centers and Programs in partnership with the Department of Developmental Services.

Overview of Developmental Disabilities
Your SLS Training Toolbox

Information Brief
Developmental Disabilities*

What is a Developmental Disability?

According to a California law called the Lanterman Developmental Disabilities Services Act, a developmental disability:

• begins before someone reaches 18 years of age;
• is something that goes on throughout a person’s life;
• is a substantial disability for the individual; and
• often means there is a need for some kind of assistance in daily living.

Included are mental retardation, cerebral palsy, epilepsy and autism. Also included are people who need the same kinds of support as those who have mental retardation. It does not include people who have only physical, learning or mental health challenges.

What Causes a Developmental Disability?

A number of things can cause a developmental disability:

• **Before birth causes**
  For example, the mother has a serious illness, has poor eating habits, poor health care, smokes, drinks alcohol or uses drugs. Developmental disabilities can also be caused by things that are inherited or by chemical or chromosome differences (like Down Syndrome).

• **During birth causes**
  For example, a lack of oxygen to the brain, low weight, or a difficult birth.

• **After birth causes**
  For example, serious accidents, abuse, lead poisoning, or poor nutrition.

Often the cause is not known. A developmental disability can happen in any family.

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What Are the Major Kinds of Developmental Disabilities?

The following are the major kinds of developmental disabilities:

**Mental Retardation**
The legal definition has to do with how an individual scores on an intelligence test and how intelligence affects a person's ability to do certain things. However, it is easier to explain that people with mental retardation are likely to:

- learn more slowly;
- have a hard time remembering things that are learned;
- have a hard time using what is learned in a new situation;
- think about things in more real-life or concrete ways; and
- keep learning and developing throughout life like all of us.

There are different levels of mental retardation from mild to moderate to severe. This means that people need different types of assistance in daily living.

Mental retardation is very different from mental illness. Some people who have mental retardation also have mental illness, but most people who have mental illness do not have mental retardation.
Cerebral Palsy
Cerebral palsy is a condition caused by damage to the brain which often happens before, during or shortly after birth. "Cerebral" refers to the brain, and "palsy" to a condition which affects physical movement. As with mental retardation, this condition can range from mild to severe. People with cerebral palsy may have:

- awkward or involuntary movements
- poor balance
- unusual walk
- poor motor coordination
- speech difficulties

Cerebral palsy is not a disease and you can't catch it. While it doesn't usually get worse, people can lead more independent lives through physical therapy and the use of special devices (for example, computers, and wheelchairs). Individuals with cerebral palsy may also have mental retardation and/or epilepsy.

Autism
Autism affects people in many different ways. The causes are not very well understood. Some people who have autism also have mental retardation. People with autism may:

- have a hard time making friends;
- get happy or upset about things that don't make sense;
- have a difficult time communicating with other people;
- hurt themselves; and
- want to stick to a certain way of doing things and get upset if things get changed around

Epilepsy
Epilepsy is a physical condition that occurs when there is a sudden, brief change in how the brain works. When brain cells are not working well, a person may become unconscious, or his/her movement, or actions may be very changed for a short time. These changes are called epileptic seizures. Epilepsy is sometimes called a seizure disorder. Individuals with epilepsy may also have mental retardation, cerebral palsy or autism.

Other
Includes people who need the same kinds of support as those who have mental retardation. It does not include people who have only physical, learning or mental health challenges. Examples are conditions like Neurofibromatosis, Tuberous Sclerosis and Prader-Willi Syndrome.

What is a Developmental Delay?

A developmental delay is a very large difference between a young child's (up to 36 months of age) abilities and what is usually expected of children of the same age. Infants and toddlers who have a developmental delay can receive early intervention services. These services support the child in learning the things that will help him/her start to catch up.
In talking and writing about people with disabilities, remember it’s people first, the disability comes second. The subtle difference between calling Joe “a person with mental retardation” rather than a mentally retarded person is one which acknowledges Joe as a person first.

AVOID:

victim
invalid
crippled
afflicted with
suffers from
DDs
TMRs
EMRs
confined to a wheelchair
mongoloid
the retarded
the handicapped
mentally deficient
patient

USE:

individual with a developmental disability
individual with a seizure disorder
individual with cognitive disabilities
a person who is non-ambulatory
individual with Down Syndrome
individual
person
participant
worker
student

* Adapted from Put in a Good Word for Me, North Los Angeles County Regional Center.
Learning the Language*

➜ Speak of the person first, then the disability,

➜ Emphasize abilities, not limitations. “For example, he uses a wheelchair” or “she walks with crutches.”

➜ Understand that although a disability may have been caused by a disease, the disability itself is not a disease and is not contagious

➜ Don’t label people as part of a disability group-say ‘people with disabilities’ not ‘the disabled.’

➜ Don’t patronize or give excessive praise or attention.

➜ Don’t say, “Isn’t it wonderful how he has overcome his disability?” People live with a disability—they have to overcome attitudinal, social, architectural education, transportation and employment barriers—not the disability,

➜ Be aware that choice and independence are important. Ask a person with a disability if s/he wants assistance before you help. Your help may not be wanted or needed.

➜ Treat adults with disabilities as adults. Call the person by his or her first name only when extending that familiarity to all others present. Make eye contact and speak directly to the person, not a companion or interpreter. Do not give the person a nickname s/he does not usually use, say “Bill” not “Billy.”

➜ Be aware of the distinction between disability and handicap. A disability is a functional limitation that interferes with a person’s ability to walk, hear, talk, learn, etc. A handicap is a physical or attitudinal constraint that is imposed upon a person. Use handicap to describe a situation or barrier imposed by society, the environment or oneself.

➜ Be considerate of the extra time it might take for a person to get things said or done.

• from Community Interface Services, San Diego, CA (Through a PDF Grant from San Diego Regional Center).
I am a “resident”. You reside.

I am admitted. You move in.

I have “behavior problems”. You are rude.

I am “non-compliant”. You don’t like being told what to do.

When I ask you out to dinner, it’s an “outing”. When you ask someone out, it’s a date.

I don’t know how many people have read the progress notes people write about me. I don’t even know what’s in there. You didn’t speak to your best friend for a month after she read your journal.

I make mistakes during my check-writing program. Someday I might get a bank account. You forgot to record some withdrawals from your account, and the bank called to remind you.

I wanted to talk with the nice-looking person behind us at the grocery store. I was told that it was “inappropriate” to talk to strangers. You and your spouse met each other for the first time in the produce department when you helped him find bean sprouts.

I celebrated my birthday yesterday with five other “residents” and two staff members. I hope my family sends a card. Your family threw you a surprise party. It sounded wonderful.

My case manager sends a report every month to my guardian informing her of everything I did wrong and some of the things I did right. You’re still mad at your sister for telling your mom about the speeding ticket you got.

I’m on a special diet because I’m five pounds over my ideal body weight. Your doctor gave up on your weight loss program.

I’m learning household skills. You don’t do housework because you hate it.

I’m learning leisure skills. You call yourself a couch potato.

After I do my budget program tonight, I get to go to McDonald’s if I have enough money. You use your charge card at the new French restaurant.

My case manager, RN, OT, PT, nutritionist and house staff set goals for me for the next year. You haven’t decided what you want out of life.

Someday I’ll be discharged…if I’m lucky. You will move upward and onward on your career path.
History of the Service System and Supported Living Services
Information Brief

A Brief History of Developmental Disabilities Services

Three Major Changes

There have been three major changes in how citizens in general have thought about people with developmental disabilities. These views have changed the way that services for individuals and families are provided:

1. **Taken Care Of.** Up until the 1960s, citizens thought that individuals with developmental disabilities should be taken care of and that this could be best accomplished in an institution away from the community.

2. **Education and Training.** From the mid-1960s to the mid-1980s, citizens began to see that individuals with developmental disabilities could grow and learn through education and training. During these years, special schools, training programs and group homes were developed in large numbers in communities throughout the United States.

3. **Community Members.** From the mid-1980s to the present, citizens began to see individuals with developmental disabilities as their neighbors, co-workers, friends and fellow community members. Now the focus is on providing the services that individuals and families need and want in the communities of their choice.

These major changes in the attitudes of citizens as well as in the way services are provided were largely due to: (1) the public education efforts of the families of individuals with developmental disabilities; (2) changes in the national and state laws; and (3) individuals with developmental disabilities speaking up for themselves.

In California

In California, institutions were the primary way that people with developmental disabilities were served through the mid-1960s. In fact, there was a demand for building more institutions. However, a study by the California Legislature showed that not everyone needed institutional services and that the cost of building more would be very high.

This study encouraged the Legislature to look for alternatives. In 1966, the Legislature funded two pilot regional centers. Their focus was on supporting individuals in their home communities as an alternative to living in a state institution. Those first two regional centers were so successful, the Legislature funded a total of twenty-one as well as a system of community-based services.

In 1972, the Legislature expanded the law to include people with mental retardation, cerebral palsy, epilepsy, autism, and other neurological problems under the term developmental disability. The law that created the service system for individuals with developmental disabilities is called the Lanterman Act.
### Paradigm Shifts in Developmental Disabilities Services*

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* Adapted from Harbor Regional Center
Information Brief

The Values of Developmental Disabilities Services in California*

Services for people with developmental disabilities in California are based on an important set of values. These values can be found in the Lanterman Developmental Disabilities Services Act (the Lanterman Act). This is the piece of legislation that helped start our current statewide system of services back in the 1970s. It begins by mentioning that a vision for the future of California is one where individuals with developmental disabilities can participate in everyday life with their friends, neighbors and co-workers.

It also mentions that services for people with developmental disabilities are based on the values of choice, relationships, regular lifestyles, health and well-being, rights and responsibilities, and satisfaction. Below is a brief description of those values.

Here is what California law (the Lanterman Act) says about the value of choice:

- services and supports should be based on the individual and his/her needs and preferences;
- individuals (with help from parents, legal guardians or conservators when needed) should take part in decisions about their own lives (like where and with whom they live, their relationships with others, the way in which they spend their time and setting goals for the future);
- people need to have a chance to practice making decisions and choices;
- an individual’s choice (or parents, conservator or guardian where support is needed) of service providers should be honored; and
- services and supports should change based on the changing needs or preferences of an individual.

Here is what California law says about the value of relationships:

- people with developmental disabilities have the right to develop relationships, marry, be part of a family and to be a parent if they choose;
- support may be needed to develop intimate relationships (like transportation, family counseling or training in human development and sexuality);
- support may be needed to help people start and keep relationships with friends and other community members.

Adapted from *Looking at Life Quality*, Department of Developmental Services (1996).
Here’s what California law says about the value of **regular lifestyles**:

- people should have a chance to be involved in the life of their community in the same ways as their neighbors, friends and fellow community members;
- services should be provided whenever possible in the home and community settings where people live and work;
- cultural preferences should be honored;
- individuals should have the training needed to be as independent and productive as possible;
- when an individual’s needs change, services should be changed as well to make sure that people can stay living where they choose to live;
- people should be comfortable where they live, have privacy when they need it and should have a say in the way their living space is decorated and arranged; and
- there should be services and supports which would allow minors with developmental disabilities to live with their families whenever possible.

Here’s what California law says about the value of **health and well-being**:

- people have a right to be free from harm and to live a healthy lifestyle;
- individuals should have a chance to learn how to keep themselves safe or have services and supports which will provide safety;
- individual's have a right to quick medical, mental and dental care and treatment when they need it; and
- people should have a chance to learn how to keep themselves healthy or have services and supports which will keep him/her healthy.

Here’s what California law says about the value of **rights and responsibilities**:

- people with developmental disabilities have the same basic legal rights as other citizens;
- individuals with developmental disabilities have a right to treatment and habilitation, dignity, privacy, and humane care, prompt medical care and treatment, religious freedom, social interaction, physical exercise and to be free from harm;
- people have the right to make choices in their own lives, such as where to live, who to live with, who to have relationships with, education and employment, leisure and planning for the future;
- along with all of these rights are responsibilities, such as respecting the privacy of others, and being an informed voter; and
- individuals should have a chance to learn about their rights and responsibilities and how to advocate for themselves.

Here’s what California law says about the value of **satisfaction**:

- individuals should have a chance to plan goals for the future and to work towards them;
- individuals should be satisfied with the services and supports they receive and should have a chance to change them when they are not satisfied; and
- people should have a chance to have a good quality life.
Agencies that Are Part of the Developmental Disabilities Service System
In California, many services for people with (or ‘at risk’ of) a developmental disability are coordinated through a network of twenty-one, non-profit regional centers established by the Lanterman Act. If a person is eligible, regional centers provide planning and related services including service coordination. Service coordinators help individuals and families with information, guidance, and assistance in accessing and using appropriate generic services and natural supports.

If the service is related to the person’s developmental disability and is included on the Individual Program Plan (the IPP is developed by an individual and his/her planning team. It states the goals that an individual is trying to achieve and the services and supports needed to reach those goals), a regional center may purchase the service from an approved service provider. Here are some typical services provided through a regional center:

- Advocacy – assisting individuals to get needed services from community and government agencies;
- Assessment and consultation – gathering information about individual service needs and supports;
- Positive Behavior Support – classes and individual consultation around positive behavior supports;
- Early intervention programs – for children not yet in public school; includes neighborhood preschools, and infant development programs with involvement by parents and other specialists;
- Independent/Supported living – services and supports for adults to live more independently in their own homes;
- Medical – identifying and accessing needed health services, typically (but not always) paid for by private insurance or government health care programs (for example, county hospitals; Medi-Cal fee-for-service; EPSDT; CCS; etc.);
- Residential – licensed or certified residential options including long-term health care facilities, foster family homes, community care homes and family home agencies;
- Respite Care – added help for the family in order to provide a break from care-giving responsibilities (may involve nursing or positive behavior support as needed);
• Social/Recreational – locating a variety of social/recreational activities through various community organizations;

• Therapy and Counseling – referral to various therapists and public or private mental health agencies; and

• Vocational – assistance in accessing a variety of work-related services and supports that include job placement, job coaching, training for employment, sheltered work and pre-vocational programs, some of which are funded by regional centers, others of which are funded through the Department of Rehabilitation.

In addition to the aforementioned responsibilities, the Lanterman Act requires that the Regional Centers be accountable for the monies received to provide services and supports for individuals. The Regional Center is required to:

• Live within a budget each year.

• Locate and/or develop innovative and cost-effective ways to achieve the desired outcomes for individuals.

• Secure services from qualified service providers and only continue those services where there is reasonable progress and agreement.

• Take into account parental responsibility for minor individuals when making a decision about the purchase of a service or support (this is also known as share of cost).

• Fund only for those services and supports which are required for the individual and that are above what a parent would provide for a child without a disability.

• Pursue all possible sources of funding before accessing Regional Center funds (Regional Centers are considered to be the payer of last resort).

• Ensure that the Regional Center does not pay for services and supports which should be provided by a generic agency such as the Department of Education, Medi-Cal and Social Security.

• Ensure that community service providers provide good quality services for a fair price (services must be cost effective).
Information Brief

Other Agencies Established by the Lanterman Act

In addition to Regional Centers, the Lanterman Act established the agencies necessary to fund and monitor the developmental service system.

**Department of Developmental Services.** The Department of Developmental Services (DDS) is the department in the California Health and Welfare Agency which has the responsibility of providing statewide policy direction and leadership to ensure that persons with developmental disabilities shall have the opportunity to lead more independent, productive and satisfying lives as envisioned by the Lanterman Act.

In order for the State of California to carry out many of its responsibilities to persons with developmental disabilities, the state, through DDS, contracts with Regional Centers to provide the service coordination necessary to obtain the services and supports best suited to each individual.

**Vendor or Service Provider Agencies.** Vendor or service provider agencies are those agencies which have been vendorized by the Regional Center to provide specific developmental services (e.g., supported living, day or residential services, respite). Vendorization is the process that an agency must complete in order to receive state funds for services. It also ensures that the provider has met all Title 17 requirements. The application requirements are different for each type of service (e.g., qualifications of staff). The Regional Center approves or disapproves the vendor application. The rates for some categories of service are established by the Department of Developmental Services while others are determined by the Regional Center.

**State Council on Developmental Disabilities.** The State Council on Developmental Disabilities is a federally mandated and funded organization charged with promoting the development of an individual and family centered, comprehensive system of services and supports for individuals with developmental disabilities. The goals are to enable individuals to achieve independence, productivity and integration and inclusion into the community.
A key responsibility of the Council is to formulate the State Plan that establishes goals and objectives for improving and enhancing the service system in California. To ensure that local needs and priorities are being addressed, the Council funds the thirteen (13) regional Area Boards on Developmental Disabilities.

**Area Boards.** Because of the vast size, complexity and diversity of the State of California, Area Boards were established to ensure that the legal, civil and service rights of persons with developmental disabilities are adequately guaranteed. Area Boards work within their specific geographic region to accomplish the same goals as the State Council.

**Protection & Advocacy, Inc. (PAI)**
Provides a variety of advocacy services for people with disabilities, their families and advocates. These services include: information about legal rights, referral to other advocacy services, technical assistance, advocacy training and, direct representation in administrative hearings and in court.
Information Brief
A Brief Description of Major Agencies

The following are the major state agencies in the developmental disabilities services system in the State of California:

**Health and Human Services Agency**
The umbrella agency for the Departments of Social Services, Health Services, Developmental Services, Mental Health and Rehabilitation.

**Department of Social Services (DSS)**
The Community Care Licensing Division licenses homes for children and adults with developmental disabilities.

**Department of Health Services (DHS)**
Administers the Medi-Cal program that pays for health care. Also, licenses and monitors homes for people with developmental disabilities and significant health needs.

**Department of Developmental Services (DDS)** Contracts with 21 Regional Centers to provide services to children and adults with developmental disabilities including service coordination and funding of services which cannot be provided by generic, community agencies. DDS is also responsible for managing the state developmental centers.

**Department of Mental Health** Oversees county mental health services.

**Department of Rehabilitation (DR)**
Furnishes funding for Work Activity Programs (WAP) which included work support services in sheltered and community-based employment settings.

**Department of Education (DOE)**
Manages special education programs in public school system. **Special Education**
Local Planning Agencies (SELPA)
Determine own structures to provide programs to students. **Local School Districts** Provide classes and training to children with disabilities.

**State Council on Developmental Disabilities (SCDD)** Develops a state plan which looks at the future of developmental disabilities services; reviews and comments on budgets and regulations of state agencies which provide services to people with developmental disabilities; and funds the Area Boards.

**Protection and Advocacy (PAI)** Protects the civil and service rights of Californians with developmental disabilities through legal advocacy.

**Area Boards** Protects the rights of Californians with developmental disabilities through public information, education, monitoring policies and practices of publicly funded agencies.

**Organization of Area Boards (OAB)** Coordinates and supports the activities of local Area Boards.
Information Brief
Regional Center Locations

Alta California Regional Center
2135 Butano Drive
Sacramento, CA 95825
Phone: (916) 978-6400 Fax: (916) 489-1033
Areas served by the regional center: Colusa, Placer, El Dorado, Alpine, Sierra, Nevada, Sacramento, Yuba, Yolo and Sutter Counties.

Central Valley Regional Center
5168 North Blythe
Fresno, CA 93722
Phone: (559) 276-4300 Fax: (559) 276-4450
Areas served by the regional center: Merced, Mariposa, Madera, Fresno, Kings and Tulare Counties.

Eastern Los Angeles Regional Center
1000 S. Fremont Avenue
P.O. Box 7916
Alhambra, CA 91802-7916
Phone: (626) 299-4700 Fax: (626) 281-1163
Areas served by the regional center: East Los Angeles, Northeast Los Angeles, Whittier District, Alhambra District.

Far Northern Regional Center
1900 Churn Creek Road, #319
P.O. Box 492418
Redding, CA 96002
Phone: (530) 222-4791 Fax: (530) 222-6063
Areas served by the regional center: Butte, Glenn, Shasta, Siskiyou, Tehama, Modoc, Plumas, Lassen and Trinity Counties.

Golden Gate Regional Center
120 Howard Street, Third Floor
San Francisco, CA 94105
Phone: (415) 546-9222 Fax: (415) 546-9203
Areas served by the regional center: San Mateo, Marin and San Francisco Counties.

Harbor Regional Center
21231 Hawthorne Blvd.
Torrance, CA 90503
Phone: (310) 540-1711 Fax: (310) 540-9538
Areas served by the regional center: Bellflower, Harbor, Long Beach and Torrance Health Districts.

Inland Regional Center
674 Brier Drive
P. O. Box 6217
San Bernardino, CA 92412-6217
Phone: (909) 890-3000 Fax: (909) 890-3001
Areas served by the regional center: Riverside and San Bernardino Counties.

Kern Regional Center
3200 North Sillect Avenue
Bakersfield, CA 93308
Phone: (661) 327-8531 Fax: (661) 324-5060
Areas served by the regional center: Kern, Inyo and Mono Counties.

Lanterman Regional Center
3440 Wilshire Blvd., Suite 400
Los Angeles, CA 90010
Phone: (213) 383-1300 Fax: (213) 383-6526
Areas served by the regional center: Pasadena, Hollywood, Wilshire, Central Los Angeles, Glendale/ Foothill.

North Bay Regional Center
10 Executive Court, Suite A
P.O. Box 3360
Napa, CA 94558
Phone: (707) 256-1100 Fax: (707) 256-1112
Areas served by the regional center: Napa, Sonoma and Solano Counties.
North Los Angeles County Regional Center
15400 Sherman Way, Suite 300
Van Nuys, CA 91406
Phone: (818) 778-1900 Fax: (818) 756-6140
Areas served by the regional center: San Fernando, Antelope, Santa Clarita, Conejo Valleys.

Redwood Coast Regional Center
808 E Street
Eureka, CA 95501
Phone: (707) 445-0893 Fax: (707) 444-3409
Areas served by the regional center: Humboldt, Del Norte, Mendocino and Lake Counties.

Regional Center of the East Bay
7677 Oakport Street, Suite 1200
Oakland, CA 94621
Phone: (510) 383-1200 Fax: (510) 633-5020
Areas served by the regional center: Alameda and Contra Costa Counties.

Regional Center of Orange County
801 Civic Center Drive West
P.O. Box 22010
Santa Ana, CA 92702-2010
Phone: (714) 796-5222 Fax: (714) 547-4365
Area served by the regional center: Orange County.

San Andreas Regional Center
300 Orchard City Drive, Suite 170
Campbell, CA 95008
Phone: (408) 374-9960 Fax: (408) 376-0586
Areas served by the regional center: San Benito, Monterey, Santa Clara and Santa Cruz Counties.

San Diego Regional Center
4355 Ruffin Road
San Diego, CA 92123
Phone: (619) 576-2996 Fax: (619) 576-2873
Areas served by the regional center: San Diego and Imperial Counties.

San Gabriel/Pomona Regional Center
761 Corporate Center Drive
Pomona, CA 91768
Phone: (909) 620-7722 Fax: (909) 622-5123
Areas served by the regional center: San Gabriel, Pomona, Monrovia, Glendora and El Monte.

South Central Los Angeles Regional Center
2160 West Adams Blvd.
Los Angeles, CA 90018
Phone: (323) 734-1884 Fax: (323) 730-2286
Areas served by the regional center: Compton, San Antonio, South Los Angeles, Southeast Los Angeles and Southwest Los Angeles Health Districts.

Tri-Counties Regional Center
520 East Montecito Street
Santa Barbara, CA 93013
Phone: (805) 962-7881 Fax: (805) 966-5935
Areas served by the regional center: Ventura, Santa Barbara and San Luis Obispo.

Valley Mountain Regional Center
7109 Danny Drive
P.O. Box 692290
Stockton, CA 95269-2290
Phone: (209) 473-0951 Fax: (209) 473-0256
Areas served by the regional center: Amador, Calaveras, San Joaquin, Stanislaus and Tuolumne.

Westside Regional Center
5901 Green Valley Circle, Third Floor
Culver City, CA 90230
Phone: (310) 337-1155 Fax: (310) 649-2033
Areas served by the regional center: Inglewood and Santa Monica West Health Districts.
Information Brief

Area Board Locations

Area Board I
Del Norte, Humboldt, Lake, Mendocino
P.O. Box 245
Ukiah, CA 95482
(707) 463-4700  Fax: (707) 463-4752

Area Board II
Butte, Shasta, Glenn, Siskiyou, Lassen, Tehama, Plumas, Modoc, Trinity
1367 E. Lassen Ave., #B3
Chico, CA 95926
(530) 895-4027   Fax: (530) 899-1562

Area Board III
Alpine, Sacramento, Colusa, El Dorado, Sutter, Nevada, Yolo, Placer, Yuba, Sierra
1010 Hurley Way, Ste. 195
Sacramento, CA 95825
(916) 263-1150   Fax: (916) 263-1155

Area Board IV
Napa, Solano, Sonoma
236 Georgia St., Suite 201
Vallejo, CA 94590
(707) 648-4073   Fax: (707) 648-4100

Area Board V
Alameda, Contra Costa, Marin, San Francisco, San Mateo
360 22nd Street, Ste 730
Oakland, CA 94612
(510) 286-0439   Fax: (510) 286-4397

Area Board VI
Amador, Calaveras, Tuolumne, San Joaquin, Stanislaus
250 Cherry Lane, Ste 113
Manteca, CA 95336
(209) 239-6700   Fax: (209) 239-3081

Area Board VII
Monterey, San Benito, Santa Cruz, Santa Clara
359 Northlake Drive
San Jose, CA 95117-1261
(408) 246-4355   Fax: (408) 246-6658

Area Board VIII
Mariposa, Madera, Merced, Fresno, Kings, Tulare, Kern
770 East Shaw Ave., Suite 123
Fresno, CA 93710
(559) 222-2496   Fax: (559) 248-2886

Area Board IX
San Luis Obispo, Santa Barbara, Ventura
7127 Hollister Ave., Ste 22
Goleta, CA 93117
(805) 685-8395   Fax: (805) 685-4896

Area Board X
Los Angeles
411 North Central Ave., Suite 620
Glendale, CA 91203-2020
(818) 543-4631   Fax: (818) 543-4635

Area Board XI
Orange
250 S. El Camino Real, Ste 110
Tustin, CA 92680
(714) 731-4787   Fax: (714) 731-4787

Area Board XII
Inyo, Mono, Riverside, San Bernardino
1960 Chicago Ave., Ste E8
Riverside, CA 92507
(909) 782-3226   Fax: (909) 781-0896

Area Board XIII
San Diego, Imperial
4711 Viewridge Ave., Suite 160
San Diego, CA 92123
(619) 637-5563   Fax: (619) 637-5572
Information Brief
Protection and Advocacy, Inc.
Locations and Contact Numbers

• E-mail: legalmail@pai-ca.org

• Toll Free - Legal Offices/TDD - - 1-800-7765746

• Toll Free - Office of Patients’ Rights - - 1-800-254-5166

• Administrative Office, 100 Howe Avenue, Suite 185-N
  Sacramento, CA 95825 (916) 488-9955

• Sacramento Legal Office, 100 Howe Avenue, Suite 235-N,
  Sacramento, CA 95825 (916) 488-9950

• Southern California Legal Office, 3580 Wilshire Blvd.,Suite 902, Los Angeles, CA
  90010 (213) 427-8747

• Bay Area Legal Office, 449 15th Street, Suite 401
  Oakland, CA 94612 (510) 839-0811

• Office of Patients’ Rights, 100 Howe Avenue, Suite 240-N
  Sacramento, CA 95825 (916) 575-1610
Individual Rights, Laws and Regulations
Information Brief
Basic Rights

Constitutional Rights
Individuals with developmental disabilities have the same rights as everyone else under the Constitution of the United States and the California Constitution. Those rights include:

- Freedom of Speech
- Right to Due Process
- Freedom of Religion
- Freedom of Association
- Freedom of Assembly
- Equal Protection of the Law
- Right to Privacy

In addition, the United States and California governments have passed statutes, which set out particular rights for individuals who have developmental disabilities.

Citizens of the State of California
In California, the Lanterman Act spells out these rights:

- A right to treatment and habilitation services and supports.
- A right to dignity, privacy and humane care.
- A right to participate in an appropriate program of publicly supported education.
- A right to prompt medical care and treatment.

Denial of Rights
Most individual rights may not be denied for any reason. A few rights may be denied for a limited period of time and under a very narrow set of circumstances called the Denial of Rights Procedure. These rights may be denied only when certain conditions are documented and the denial is approved by the regional center.
Information Brief

Rights of Individuals Receiving Supported Living Services

The Lanterman Act and the SLS regulations state that individuals receiving SLS shall have the right to make decisions that shape the nature and quality of their lives. Individuals in SLS have the following rights:

To choose where they live.

To choose who they live with, if anyone.

To control the environment (character and appearance) within their own home.

To receive services and supports that change as their needs change without having to move elsewhere.

To choose and change their SLS vendors and direct service staff.

To receive services based on their needs and preferences.

To receive services and supports that assist them to exercise choice in his or her life while building critical and durable relationships with other individuals.

Throughout this toolbox on supported living services you will learn more about how these rights are implemented in supported living services.
What is the Individual Complaint Process?

The Individual Complaint Process permits each individual or any representative acting on their behalf, to pursue a complaint either against the regional center, developmental center or a service provider.

If I Believe My Rights Have Been Violated To Whom Do I Complain?
Your complaint should be made to the clients' rights advocate assigned to the regional center from which you receive case management. (You can phone 1-800-390-7032.)

How is This Different from Fair Hearing?
A Fair Hearing is a procedure for resolving disagreements between the regional center and individuals or applicants. It may be used to appeal the nature, scope or amount of services. The disagreements may be about services, an eligibility decision or any action concerning services and supports of the regional center with which you disagree. Contact your clients’ rights advocate if you need information regarding this process.

Individual Complaint Process
The complaint may be about any right to which the individual is entitled which the individual or their representative believes has been violated, punitively withheld, or improperly or unreasonably denied.

What Will the Client’s Rights Advocate Do?
Within ten working days of receiving your complaint, the client's rights advocate should investigate and send you a written proposed resolution.

What if I am not Satisfied with the Decision of the Clients' Rights Advocate?
If you are dissatisfied with the action taken or proposed, the clients' rights advocate shall, within five working days, refer you to the regional center or developmental center director.

What Will the Regional Center Director Do About My Complaint?
The Regional Center Director shall receive and seek to resolve second level complaints within ten working days.

What if I am not Satisfied with the Decision of the Regional Center Director?
If you are not satisfied with the decision made by the regional center director you must notify the regional center director. Within ten working days of receipt of your notification, the regional center director shall refer the complaint to the director of the department. The director of the department shall, within 45 days of receiving the complaint, issue a written administrative decision to the regional center and send a copy to you.

How Will I know What to do if My Rights have been Denied?
All individuals, or where appropriate, their parents, legal guardian, conservator, or authorized representative shall be notified in writing in a language which they comprehend, of the right to file a complaint when they apply for services from a regional center or at each regularly scheduled planning meeting.
Information Brief

Appealing Regional Center Decisions

The Regional Center is frequently in a position to approve and authorize services and supports (unless provided by a generic service agency). However, there will be times when a request from an individual or family is not approved. If an individual or family decides to appeal a decision, the service coordinator is required to send a notice of action which includes information on appeals and fair hearings and advocacy resources. The individual or family is given information on how to present their appeal so that a fair decision can be made.

Here is a summary of the general procedures that both the Regional Center and the applicant [for services] or recipient [of services] or an authorized representative must follow in the appeal of a decision:

1. Any time the Regional Center proposes certain actions without the mutual consent of the applicant [for services] or recipient [of services] or an authorized representative, the Center must send a notice of action. Those actions requiring a notice are:
   - To reduce, terminate or change services that are included in the IPP;
   - To determine that a recipient is no longer eligible for services;
   - To deny initiation of a service or support requested for inclusion in the IPP; or
   - To deny eligibility to an applicant.

2. If the Regional Center proposes to reduce, terminate or change services that are included in the IPP, the Center must send the recipient [of services] the notice 30 days prior to the proposed action. If the Regional Center determines that someone is no longer eligible for services, the Center must send the recipient [of services] the notice within 30 days of the proposed action. Anytime a service is requested and the Regional Center makes a decision to deny that request, the Center must within 5 days send out a written notice with a reason for denying that service.

3. As a result of that notice, a fair hearing may be requested by any applicant or recipient of services or authorized representative who disagrees with the decision made by the Regional Center. The individual must initiate the request for a fair hearing within 30 days of the receipt of the notice. If an individual is currently receiving service from the Regional Center and he/she wishes to continue receiving the service while appealing a decision, he/she must notify the Center of this desire by filing a request for a fair hearing within 10 days from the receipt of the notice.

If an individual is not currently receiving service, he/she does not have a right to receive the requested service during the appeal process.
A fair hearing may also be requested for any other action or proposed action which the individual believes to be illegal, discriminatory or not in the best interest of the recipient or applicant.

4. A request for a hearing or mediation must be on a form supplied by the Regional Center. If a Regional Center employee receives a verbal request for a fair hearing that employee must provide the recipient, applicant or authorized representative (claimant) with a hearing request form. If the individual requests assistance the service coordinator must assist in filling out the form.

5. Immediately upon receiving a Fair Hearing Request form, the Regional Center Director or his/her designee, shall offer in writing to meet informally with the claimant or his/her authorized representative within 10 days of the date the hearing request form is postmarked or received by the Regional Center, whichever is earlier. Notification that the claimant or his/her authorized representative may decline an informal meeting must be provided at the time the offer is made. At this time, the claimant may proceed to either mediation or directly to fair hearing.

6. If the claimant or his/her authorized representative accepts the opportunity for an informal meeting and is satisfied with the decision of the Regional Center following the meeting, he/she shall submit to the Regional Center a completed Fair Hearing Request Withdrawal form, withdrawing the request for a fair hearing.

7. If the claimant or his/her authorized representative has declined an informal meeting or is dissatisfied with the decision following the informal meeting, the matter shall proceed to either mediation or a fair hearing.

8. If the claimant or his/her authorized representative has elected to pursue mediation, the Regional Center must either accept or decline the mediation within 5 days of receipt of the written request from the claimant or his/her authorized representative. The mediation must be held within 20 days of the date the request form is postmarked or received by the regional center, whichever is earlier. If the issue or issues involved in the mediation are resolved to the satisfaction of both parties, the mediator shall prepare a written resolution. Agreement of the claimant or his/her authorized representative to the final solution shall be accompanied by a withdrawal, in writing, of the fair hearing request. If there is no resolution, the matter shall proceed to fair hearing.

9. If dissatisfied with the decision of the informal meeting or a resolution through mediation cannot be made or mediation is waived, the individual may request a fair hearing with the California Department of Developmental Services. To request a state level fair hearing, the individual completes the bottom-
portion of the hearing request form and returns it within ten (10) days to the Regional Center. The Regional Center will send the hearing request to the State Department of Developmental Services.

10. The individual or another person selected by the individual (an attorney, advocate, or friend) will be expected to present the case at the hearing. This is an administrative hearing at which the technical rules of evidence need not be applied. The hearing must convene within fifty (50) days from the date it was first requested, unless either party requests a continuance for good cause. The hearing officer will hear evidence from both parties and will issue a written decision deciding the case within ten (10) days (and no more than 80 days from the date of initial request). The hearing officer’s decision is the final administrative decision and is binding on both parties. Any final administrative decision may be appealed to a court of competent jurisdiction within ninety (90) days. A appeal to a court, however, will not stay enforcement of the administrative order. If the subject of the appeal was a termination of service and the decision is unfavorable for the claimant (individual or family), the service will be terminated ten (10) days after the notice is received by certified mail.

11. If the services in dispute were funded through a Medi-Cal waiver, the Department of Health Services will review the hearing officer's decision and either adopt or modify it.

12. If the reason that the service is to be modified is lack of available funds the Regional Center will request that the Department of Developmental Services provide funding.

13. Individual rights in the fair hearing include the following:

   a. The opportunity to be present in all proceedings and to present written evidence and oral evidence.

   b. The opportunity to confront and cross-examine witnesses.

   c. The right to appear in person with counsel or other representative of his/her own choosing.

   d. The right to access records.

   e. The right to an interpreter.
## People First Statement of Rights and Responsibilities

We are PEOPLE FIRST. Our disabilities are a normal part of life. As American citizens, we have the same rights and must meet the same responsibilities as anyone. We’re entitled to the support we need to do that.

<table>
<thead>
<tr>
<th>Rights</th>
<th>Responsibilities</th>
</tr>
</thead>
<tbody>
<tr>
<td>To live like normal people.</td>
<td>To not harm ourselves or others.</td>
</tr>
<tr>
<td>To have the relationships we choose.</td>
<td>To treat others as equals and with respect.</td>
</tr>
<tr>
<td>To have the medical care we need.</td>
<td>To take care of our health and to ask for help if we need it.</td>
</tr>
<tr>
<td>To learn all we can.</td>
<td>To use what we learn.</td>
</tr>
<tr>
<td>To control our lives, take risks and make choices.</td>
<td>To be responsible for the consequences of our own actions.</td>
</tr>
<tr>
<td>To come and go as we want.</td>
<td>To be dependable and let people know where we are.</td>
</tr>
<tr>
<td>To be free and not in state hospitals.</td>
<td>To accept other places to live, and not act out on other people.</td>
</tr>
<tr>
<td>To have wishes and dreams.</td>
<td>To believe in ourselves, keep control and not get mad at ourselves.</td>
</tr>
<tr>
<td>To be respected as equals.</td>
<td>To act like an equal.</td>
</tr>
<tr>
<td>To have and express our own feelings and opinions - and to be heard and taken seriously.</td>
<td>To find out what’s right for us and speak up in whatever way we can.</td>
</tr>
<tr>
<td>To be free to ask for what we want.</td>
<td>To ask when we want something from someone.</td>
</tr>
<tr>
<td>To stand up for ourselves to people, agencies and the government.</td>
<td>To be strong, face our fears and ask for help when we need it.</td>
</tr>
<tr>
<td>To live free from abuse.</td>
<td>To tell if someone is harming us.</td>
</tr>
<tr>
<td>To work.</td>
<td>To do the job right.</td>
</tr>
<tr>
<td>To have fun.</td>
<td>To not hurt anyone in the process.</td>
</tr>
<tr>
<td>To get information from professionals.</td>
<td>To think about the information we get.</td>
</tr>
<tr>
<td>To have privacy.</td>
<td>To ask for a place away from people.</td>
</tr>
</tbody>
</table>

If you have questions or want more information, contact:
CALIFORNIA PEOPLE FIRST, P.O. BOX 3969, Chico, CA 95927
**Information Brief**

**Advocacy**

**Advocacy is:**

- Helping people help themselves
- Building self confidence
- Supporting independence
- Telling people their rights
- Telling people their options
- Providing assistance and training
- Helping locate services
- Asking people what they want
- Treating adults like adults

**Advocacy is not:**

- Taking over a person’s life
- Making a person dependent
- Doing everything for a person
- Not informing a person of his/her rights
- Making decisions for people
- Controlling people
- Treating adults like children
- Limiting options
- Knowing what is best because you are a professional
- Not respecting choices
Introduction

In addition to the Lanterman Act (see Information Brief The Values of the Developmental Disabilities Services System), there are a number of state and federal laws and regulations that will affect your job as a service provider.

The Americans with Disabilities Act (ADA)

In July 1990, Congress passed the Americans with Disabilities Act, a landmark civil rights bill that extends protection against discrimination to people with disabilities. The ADA defines disability as a mental or physical condition that limits a “major life activity” such as walking, hearing, seeing or working, covering some 900 disabilities. It requires public facilities, transportation and communication services to be accessible to people with disabilities. The bill addresses four main areas:

Employment:

- Employers may not discriminate against persons with disabilities in hiring or promotion if the individual is otherwise qualified for the job.
- Employers can ask about one’s ability to perform a job, but cannot inquire if someone has a disability or subject a person to tests that tend to screen out people with disabilities which are not job related.
- Employers must make “reasonable accommodations” for workers with disabilities, including job restructuring and modification of equipment. Employers do not need to provide accommodations that impose an “undue hardship on business operations.”

Public Facilities

- Private businesses such as restaurants, hotels, theaters and stores must not discriminate against individuals with disabilities.
- Auxiliary aids and services must be provided to individuals with vision or hearing impairments or other individuals with disabilities, unless an undue burden would result.
- Physical barriers in existing facilities must be removed, if removal is readily achievable. If not, alternative methods of providing the services must be offered, if they are readily achievable.
• All new construction and alterations of facilities must be accessible.

Transportation

• New public buses and rail cars ordered after August 26, 1990, must be accessible to persons in wheelchairs.

• At least one rail car per train must be accessible to wheelchairs.

• Transit authorities must provide comparable paratransit or other special transportation services to individuals with disabilities who cannot use fixed route bus services, unless an undue burden would result.

• New bus and train stations must be accessible.

• Key stations in rapid, light, and commuter rail systems must be made accessible by July 26, 1993, with extensions up to 20 years for commuter rail (30 years for rapid and light rail).

• All existing Amtrak stations must be accessible by July 26, 2010.

Communication

• Companies offering telephone service to the general public must offer telephone relay services to individuals who use telecommunication devices for the deaf (TDD) or similar devices.

ADA covers state and local governments

• State and local governments may not discriminate against qualified individuals with disabilities.

• All government facilities, services and communications must be accessible consistent with the requirements of Section 504 of The Rehabilitation Act of 1973.

• Public entities, including schools, must make reasonable modifications to its policies, practices or procedures to avoid discrimination, unless such a modification would fundamentally alter the nature of its service, program or activity and would create undue financial and administrative burdens.

• Alterations to existing facilities will be required if the modification is “readily achievable.” If physical modification is not readily achievable, then an alternative accommodation must be found. Some examples of facility modification are: van accessible parking, elevated walkways, lowered drinking fountains, adjusted shelves and storage areas, volume controls on telephones, installation of bathroom stalls and replacement of carpeting.

• Title 11 of ADA is modeled after those rights and privileges existing under Section 504.
• Individuals with disabilities enrolled in public schools may not be discriminated against in participating in school functions (such as field trips, recreational offerings, or athletic events.)

• Private schools are expected to provide reasonable accommodations and equal treatment for individuals with disabilities.

Rehabilitation Act of 1973, Section 504 (PL 93-112)

This law is known as the first federal civil rights law protecting the rights of people with disabilities. It states that no qualified handicapped individual...shall, solely by reason of the handicap, be excluded from the participation in, be denied the benefits of, or be subjected to discrimination under any program or activity receiving federal financial assistance.

Discrimination is prohibited in the following areas:

(1) Education
(2) Vocational education
(3) College programs
(4) Employment
(5) Health, social service programs, welfare
(6) Programs funded with federal dollars

All public education programs are covered by section 504. Students with disabilities must have the same options as others about courses, and colleges and universities must also make reasonable modifications in requirements when necessary to insure full opportunity for students with disabilities.

Section 504 also prohibits discrimination in employment. Equal employment opportunities for qualified people with disabilities must be assured by organizations receiving federal funds. In 1992, the Rehabilitation Act was amended to authorize rehabilitation services to help people with physical and mental disabilities to become gainfully employed. These services include vocational evaluation, counseling, supported employment, work adjustment and education.

Title 17, California Code of Regulations

Title 17 regulations are developed by the California Department of Developmental Services and are based on the Lanterman Act. These regulations (specifically Chapter 3 – Community Services) govern how services are delivered within the California developmental services system.

Starting with Section 50201, Title 17 covers parental fees, conflict of interest code, rules for conducting research, client rights, fiscal audits and appeals, fair hearings, vendorization procedures, Regional Center administrative practices and procedures, standards and rate-setting procedures for community-based programs and in-home respite services and residential facility care and services.
Information Brief

Protection from Abuse

Introduction
There is a special concern for the abuse of children, dependent adults and the elderly. As they are more vulnerable than others, such individuals face greater risk of abuse. It's important to know your responsibilities should you need to make a report.

**Dependent adult abuse** is defined as physical abuse, neglect, financial abuse, abandonment, isolation, abduction or other treatment with resulting physical harm of pain or mental suffering or the deprivation by a care provider of goods and services which are necessary to avoid physical harm or mental suffering. **Child abuse** is defined as physical injury which is inflicted by other than accidental means on a child by another person, sexual abuse, willful cruelty or unjustifiable punishment of a child, unlawful corporal punishment or injury and neglect.

Protection Against Abuse
You can help protect individuals from abuse through:

**Observation** - pay attention to the individuals you support. Some may not be able to tell you with words when something is wrong.

**Communication** - talk with and listen to the individuals you support.

**Conversation** - talk with others who know and care about the individuals you support.

**Documentation** - write down what you see and hear.

**Review** - your notes and conversations to look for any possible patterns.

**Report** - if abuse is known or suspected.

Reporting Requirements for Adult Abuse
An **dependent adult** is any California resident 18 to 64 years of age, who has physical or mental limitations which restrict his or her ability to carry out normal activities or to protect his or her rights, including, but not limited to, persons who have physical or developmental disabilities or whose physical or mental abilities have diminished because of age. Included is any person 18-64 years of age, regardless of physical or mental condition, who is admitted as an inpatient to a 24-hour health facility. An **elder** is anyone residing in California, who is 65 years of age or older, whether or not impaired mentally or physically.

California law requires that any person who provides care or services for elders or dependent adults (whether or not the person receives compensation) must report certain kinds of abuse.
Mandatory Reporting

Any employee of a supported living agency is considered a mandated reporter with a legal duty to report suspicion or knowledge of child, dependent adult or elder abuse. Failure to report can result in a mandated reporter being held liable for both criminal and civil consequences. Conversely, the mandated reporter has complete immunity from legal actions even if the report turns out to be false.

All allegations of abuse shall be reported by telephone as soon as possible to either Child Protective Services, Adult Protective Services or the Ombudsman’s office depending upon the age of the victim and the location of the alleged abuse. If the victim is a child, the report will be made to Child Protective Services with a written follow up report to be submitted within 36 hours. If the victim is an adult and the abuse occurred in a long term care facility, the alleged abuse is reported to the Ombudsman’s office. If the alleged abuse occurred at any other location, the report is made to Adult Protective Services. The telephone report concerning an adult shall be followed up with a written report within two working days.

Ombudsman Office
Department of Aging

Each county is required to have an office devoted to the Ombudsman. This office receives reports of abuse to dependent adults if the abuse occurs in any long-term facility (nursing homes, residential facilities, foster homes, or any licensed or unlicensed residential facility providing care and supervision).

Adult Protective Services
California Department of Social Services

Each county is required to have an office devoted to Adult Protective Services. This office receives reports of abuse to dependent adults. Each report is assigned to a case worker for investigation, assessment and referral to appropriate agencies. The law requires mandated reporters to make a verbal report immediately, followed by a written report within two working days. When the suspected victim resides in their own home and receives SLS, the abuse should be reported to the county Adult Protective Services Agency. If the abuse occurs in any long-term care facility (nursing homes, residential facilities, foster homes, or any licensed or unlicensed facility providing care and supervision), it must be reported to the local ombudsman program.
Elder and Dependent Adult Abuse
(excerpted from Los Angeles Infoline)

Quick Checklist. When an elderly person or dependent adult is being abused, neglected or exploited, prioritize for safety:

1. Is the person being injured or otherwise endangered at that moment? If YES, call the police or paramedics.
2. Is the suspected abuse occurring in a residential facility or adult day health center? If YES, report to the local Long Term Care Ombudsman.
3. Is the abuse occurring outside of a residential facility (e.g., a person living in his or her own home)? If YES, report to Adult Protective Services.

Definitions. Listed below are possible indicators of abuse (adapted from guidelines developed by Adult Protective Services):

Physical Abuse: Pushing, shoving, shaking, slapping, beating or unreasonable restraint.
Indicators: unexplained bruises, welts or burns; friction marks; bleeding scalp; detached retina; unset broken bones or other untreated injuries; any repeated injuries. Frequent emergency room visits. Frequent changes of doctors. Conflicting or implausible explanations of injuries.

Neglect: Failure to provide basic needs such as food, shelter, or medical treatment, or abandonment.
Indicators: dehydration or malnourishment; untreated bed sores; medication withheld or improperly self-administered; poor personal hygiene; soiled clothing or bedding left unchanged; keeping appliances the person needs such as bedside commode or walker out of reach; lack of clothing or other necessities; inadequate heat or ventilation; safety hazards in home.

Psychological Abuse: Verbal threats or insults, or other intimidating behavior.
Indicators: caregiver accuses the abused person of being incontinent on purpose; threatens him with placement in a nursing home.

Financial Exploitation: Mismanagement of money; theft of property.
Indicators: missing property; unpaid bills or rent; lack of clothing or other basics; unexplained bank account or auto-teller withdrawals; unexpected changes in wills or titles to property; adult’s money not being spent on clothes or other basics needs.

Other Indicators of Abuse: Abused adult is kept isolated from family or friends and not allowed to speak for himself. Caregiver resists assistance from social service agencies. Caregiver has a history of abusing others. Caregiver appears angry at elder or dependent adult. A abused person may appear fearful, withdrawn, depressed or confused (and these conditions are not caused by mental dysfunction).
Information Brief  
About Special Incident Reports*

Special incident reports are made by an SLS agency to the Regional Center when certain things occur. Some incidents just happen (like earthquakes) and some may mean that the service system needs to help an individual develop better or provide different supports. Regional Centers need to know about both of these kinds of things so that they can help the individual and the SLS agency make sure that people get the supports they need to live safely and happily on their own.

Under California state law, SLS agencies are required to let their Regional Center know when certain things occur. These things are:

- A denial of rights
- Any form of abuse
- Things that happen which may lead to criminal charges or legal action
- Serious bodily injury, serious physical harm or death
- Any time someone has to physically help someone to not hurt themselves or someone else by using emergency intervention procedures allowed by law.
- Poisonings
- Epidemic outbreaks
- Catastrophes
- Fires or explosions

The SLS agency must call the Service Coordinator at the Regional Center as soon as one or more of these things have happened, and must write a special incident report and send it to the Service Coordinator or a person designated by their regional center within one day (24 hours). The SLS agency may also have to report the incident to other people or agencies, for example, Adult Protective Services. Supported living agencies are required to train their staff in Special Incident Reporting Procedures. Also, each regional center has the responsibility of informing the supported living agency about reporting procedures and appropriate forms to use.

* Adapted from CHOICESS Supported Living Agency, Arcadia, CA.
Information Brief
Confidentiality

Introduction

Confidentiality can be a professionally and legally complex issue. Treating information confidentially means not releasing it to anyone outside the SLS agency without the express consent of the individual, a guardian (typically a parent of a child under the age of 18) or a conservator (a person appointed by a court to legally represent an adult). Under certain circumstances, information may be released without permission. The main exception to confidentiality rules arise in situations involving child or adult abuse, court orders or subpoena of records or danger to self or others. This section will explore some of the confidentiality requirements.

The Law

The Lanterman Act, specifically section 4514 (Welfare and Institutions Code), specifies that all information and records obtained in the course of providing intake, assessment and services to persons with developmental disabilities shall be confidential. Information shall be disclosed in the following situations:

a. In communications between qualified professionals employed by a Regional Center or state developmental center. Consent of the individual, parent, guardian or conservator is required before information or records can be disclosed by someone NOT employed by Regional Center, State Developmental Center or a program not vendored by either.

b. When a person with a developmental disability who has the capacity to give informed consent designates individuals to whom information may be released, a physician, psychologist, social worker, marriage, family and child counselor, nurse, attorney, or other professional may not be compelled to release information given them in confidence unless a valid release has been signed.

c. For a claim to be made on behalf of a person with a developmental disability for aid, insurance, government benefit, or medical assistance.

d. If the person, guardian or conservator designates in writing persons to whom records or information may be disclosed. Again, certain professionals may require a valid release.

e. For research, if reviewed and approved by the Director of Developmental Services. All researchers must sign an oath of confidentiality.
f. To courts, for the administration of justice.

g. To governmental law enforcement agencies for the protection of federal and state elective constitutional officers and their families.

h. To the Senate or Assembly Rules Committee for the purposes of legislative investigation.

i. To the courts as part of a Regional Center report.

j. To the attorney for the person with a developmental disability upon presentation of a release of information signed by the person. The Regional Center shall release all information for the person who lacks the capacity to give informed consent. Again, professionals may require a valid release.

k. To a probation officer who is evaluating a person after conviction of a crime if the Regional Center determines that the information is relevant to the evaluation. The confidential information remains confidential except for the purposes of sentencing. After sentencing, the confidential information is sealed.

l. Between people on the “multidisciplinary” teams dealing with prevention, identification, management or treatment of an abused child or parents.

m. When a person with a developmental disability dies while hospitalized in a state developmental center, the information related to the diagnosis and treatment of the person’s physical condition is released to the coroner.

n. To authorized licensing personnel or authorized representatives from Department of Health Services or Department of Social Services to perform their duties regarding facilities. Names which are confidential are listed in attachments which are kept separate from the other material. Representatives from these agencies typically identify people by numbers in facilities.

o. To a board that licenses and certifies professionals if there is cause to believe that a violation of law has occurred. Confidential information shall not contain the name of the person with the developmental disability.

p. To governmental law enforcement agencies when a person with a developmental disability is reported lost or missing or if there is cause to believe that a person with a developmental disability has committed or been the victim of a crime.

q. To the Youth Authority or Adult Correction Agency.

r. To an agency mandated to investigate a report of abuse.
In the event that a person, parent, guardian or conservator does not grant or denies a request to release information within a reasonable period of time, an agency may release information if the information is deemed necessary to protect the person’s health, safety or welfare. The person must have been advised annually in writing about the policies for releasing information. That policy statement can become part of the person’s IPP to comply with the notice requirement.
Information Brief

Parents and Others as Legally Authorized Representatives

There are some terms you need to know in order to understand the rights and responsibilities of parents and other legally authorized representatives.

Competence
Competence (or incompetence) is about the ability of an individual to make decisions. Until a person reaches the age of majority (age 18 in California), he/she is presumed to be incompetent. That is, not able to manage alone or to come to reasoned decisions about certain important matters. Upon reaching the age of majority, even if the person has a significant intellectual impairment, he/she is presumed to be competent.

Parents
Parents are considered natural guardians of their biological or adopted children and have certain rights and responsibilities in making decisions on behalf of their children.

Guardianship
Some minors need a court-appointed guardian if parents have died, abandoned a child, or had their parental rights removed by a court of law. The issues surrounding guardianship are few, precisely because the law presumes incompetence. Since 1981, guardianships have only been available for minors.

Conservatorship

A conservatorship is a legal arrangement in which a competent adult oversees the personal care or financial matters of another adult considered incapable of managing alone. Some parents incorrectly presume (as was traditional years ago) that as natural guardians of children their legal responsibilities continue for a child with a developmental disability if he/she has “not grown up and left the nest.”

General conservatorship
This is the conventional kind of conservatorship for adults unable to meet their own needs or manage their own affairs.

Limited conservatorship
The purpose of limited conservatorship is to protect adults with developmental disabilities from harm or exploitation while allowing for the development of maximum self-reliance. If granted by the court, the limited conservator can have decision-making authority (or be denied authority) in as many as seven areas:

1. To fix the person’s place of residence.
2. Access to confidential records and papers.
3. To consent or withhold consent to marriage.
4. The right to contract.
5. The power to give or withhold medical consent.
6. Decisions regarding social and sexual contacts and relations.
7. Decisions concerning education or training.

**Short of a special court order,** the limited conservator **may not**, however, provide substitute consent in the areas of:

2. Electroshock therapy.
3. Placement in a locked facility.
4. Sterilization.

The **limited conservator** should have:

1. Personal knowledge of the conservatee.
2. Knowledge of what constitutes the “best interest” of the conservatee.
3. A commitment to providing that which is in the person’s “best interest.”
4. Financial management skills (as appropriate).
5. A knowledge of programs and services, their availability and effect.
7. Proximity to the conservatee.
8. Availability in terms of time and energy.
Information Brief

A Brief History of the Individual Plan

In the early 1970’s, there were a number of court cases about the answer to the question:

What are the rights of people with developmental disabilities?

In general, the courts answered that people with developmental disabilities have the same rights as everyone else. While this helped, it created a new set of questions. Since everyone is different, the next question became what is the best way to make sure that individuals with developmental disabilities get the services and supports that they need? In the mid 1970’s, many federal and state laws were passed to help clear up this issue.

All of these laws state that to get the right support, a plan of service must be written that looks at each person’s individual needs. This became known as the Individual Plan. As the years have passed, lots of I (fill in the blank) P’s have been created. Here are just a few:

**Plan**
- Individual Program Plan
- Individual Education Plan
- Individual Family Support Plan
- Individual Transition Plan
- Individual Habilitation Plan
- Individual Work Related Plan
- Individual Service Plan

**Agency**
- Regional Center
  - School
- School and Regional Center
  - School
- Department of Rehabilitation
- Department of Rehabilitation
- SLS Agency

While there are some differences in all of individual plans (some are for students, some are concerned with work only, some are about support in the person’s home and community), things that all of them have in common are that they:

- are written down;
- are developed by everyone involved with the person’s life (a team approach);
- outline the things that a person can do well (strengths, preferences, capabilities) and their plans for the future (life goals);
- outline the things that get in the way (barriers) and things that a person needs help with (support needs);
- list the steps that are needed for a person to learn, live or work more independently (goals, objectives, services and supports);
- list who will help with the services (responsibilities);
- list ways to tell if the services help (progress towards goals); and
- state when the plan should be looked at again (review date).
Introduction

While Regional Center Individual Program Plans may look different, there are some things that California law (Lanterman Act, Title 17) says must be the same. This article is about those things which all Regional Centers must do when working on the IPP.

IPPs are Person-Centered

All regional centers are required to use a person-centered approach when planning for the Individual Program Plan. An IPP describes the needs, preferences and choices of the individual and family. It is developed through a process of figuring out individualized needs. The IPP changes as individual needs and preferences change.

Individual Choice

Individuals have a right to make choices and have them written into the IPP. Those choices include, where and with whom to live, the way people spend their time each day and with whom, choice about things to do for fun and plans for the future. To help individuals and families make good choices, information about different kinds of services must be presented in a way that’s easy to understand.

The Planning Team

A planning team is a group of individuals who work together to support the choices and preferences of one of the team members. The team meets to share what they have learned about the life patterns, interests and preferences of an individual from the person-centered planning process. The person-centered planning process provides the team with a picture of the strengths and abilities of the individual, as well as the challenges that he or she faces.

The planning team is made up of the individual, Regional Center service coordinator and others invited by the individual like family members, friends, neighbors, advocates and SLS staff. If an individual has a legal representative or a guardian or conservator, they must also be on the team. To make sure that individuals are able to actively participate, it may also be necessary to include a translator or interpreter on the team.

Assessment

When the planning team shares what they know about the life patterns, interests and preferences of an individual, they are completing an assessment. When the team decides that more information is needed, a specialist (for example, speech therapist, psychologist) may be asked to complete an assessment as well.
The IPP Meeting

The IPP Meeting

The Regional Center service coordinator helps schedule the meeting of the planning team. The location, time, date, and length of the IPP team meeting should meet the needs and preferences of the individual and family. The idea is to make the meeting as comfortable as possible for everyone involved. For example, some individuals may need a series of shorter meetings and others may ask for phone conferences. Sometimes, individuals and families may ask for an informal meeting place like a restaurant, barbecue or picnic.

When the team meets to develop the person-centered IPP, this is called a planning conference. One of the purposes of the meeting is to bring all the members of the team together for a face-to-face discussion. During the meeting, there are several important roles for team members:

**Team Leader.** This can be anyone on the team who wants to help keep the meeting going. It is quite often the regional center service coordinator.

**Team Recorder.** Someone who will take notes during the meeting.

**Team Members.** Everyone who comes to support the person working on the IPP.

The information discussed at the planning conference and the decisions and choices that are made become the person-centered Individual Program Plan.

The Major Parts of the IPP

The basic parts of the person-centered Individual Program Plan are:

- **Goals**
- **Objectives**
- **Services and Supports**
- **Review Date**

**Goals are the things that people want to do in the next few years.** They are the choices that people make about where to live, what to do during the day, who to spend time with, what to do for fun and hopes and dreams. Here are some examples:

- Learn how to ride the bus.
- Join a church.
- Get a job.
- Live in my own apartment.
- Learn how to ride a bike.
- Save money for a vacation.

**Objectives are the steps needed to move toward a goal.** An objective needs to have a date written into it so the team will know if the goal is getting closer.

If someone’s goal is:

Joan wants to save money for her vacation trip.

Objectives (or first steps) might be:

- By the end of January, Joan will open a savings account.
- By the end of June, Joan will have saved $50 towards her vacation trip.
If someone's goal is:
Travis wants to join a church.

Objectives (or first steps) might be:
By the end of June, Travis will have a chance to visit four churches on Sunday.

By the end of July, Travis will choose a church to join.

There are many kinds of **services and supports** that can be listed in an IPP, depending on the support needs of the individual. Some of those services and supports are:

- **a place to live** (for example, supported living, emergency housing, foster family, group home, help in finding a place, homemaker services);

- **a place to learn or work** (for example, education, day program, workshop, supported employment, competitive employment);

- **getting around** (for example, transportation, travel training, recreation, adaptive equipment); and,

- **staying healthy** (for example, counseling, mental health services, medical or dental services).

The law says that regional centers must first try to use regular community services before it can purchase service and supports from vendorized providers (for example, SLS or day services).

The plan should also have written into it some times (review dates) when everyone on the team will get together and look at how things are going. This is a time to find out if the individual (and their family if someone is under 18) is happy with their current services and supports and if there is progress towards individual goals. If things aren't going well on one of the goals or if someone is unhappy with their services and supports, then it may be time to change the plan and the services and supports.
Generic Resources
Q and A on Generic Services

**What are generic services?** They're services available to anyone in a community. However, generic doesn't necessarily mean free.

**Who are they for?** Many are a part of the public service system found in any community. Some are for people with low incomes, while others are for people who are smart shoppers looking for bargains.

**Is there a core of generic services available everywhere?** Yes. While they may be different in quantity and quality, you can find In-Home Supportive Services, Rental Assistance, Utility and Retail Discounts, Health Services, and Public Transportation services everywhere.

**How do you find out about them?** You can talk to other SLS professionals, regional center service coordinators and local government officials. You can also go to the library, senior citizen and volunteer centers. In addition, many communities have a local resource guide.

**Where do you start?** It's important to find out as much general information as you can by looking at the customer services pages of the phone book. You might also go to city hall, the local library, community college, chamber of commerce and talk to other service users and providers. You will also need to find out some specific information about what an individual needs and wants and then you start the process of matching.

**Basic Rules for Tracking Down Generic Resources**

- A request/search should be based on a real need
- If you're helping someone search, it's often better to approach service reps as someone's friend rather than a professional
- The 7 call rule - you might have to make seven calls to find the resource you're looking for
- Be cheerful, humble and optimistic
- Be concise
- Try to get something out of every effort, even if it's just another phone number
- Say thank you and return the favor whenever possible
## Typical Generic Resources*

### CONTINUING EDUCATION
- Adult education:
  - College
  - High School - Night School
  - Parks and Recreation
  - Classes offered by the city
  - Classes offered by individual businesses (e.g. craft stores, cooking supply stores)
- Community colleges - disabled student services (in-class assistance, tutoring, etc.)
- Community colleges - technology centers (adaptive equipment)
- Driver training programs
- Literacy programs
- YMCA, other organizations

### EMPLOYMENT
- Department of Rehabilitation
- Employment Development Department
- Private Industry Council
- Regional Occupational Program
- Supported employment agencies

### FOOD/MEALS
- Meals on wheels
- Food banks and pantries
- Food stamps (emergency assistance)
- W.I.C. (Women, Infants, and Children)
- Community and church assistance leagues
- SHARE - 2 hours of volunteer work + $14 = $35 worth of groceries

### HEALTH CARE
- 911 for emergency health care
- Alcoholic Anonymous, Gamblers Anonymous, Narcotics Anonymous, etc.
- Assisted living providers
- California state licensing boards (checking on medical license status, making complaints, etc.)
- County Health Department
- Doctor/Dentist referral services
- Free medications; for information call 1-800-PMA-INFO, ask for Directory of Prescription Drug Patient Assistant Programs which is free & very detailed.
- Home health nursing
- Hospice care
- Non-emergency medical transportation companies
- Pregnancy help centers

### HOUSING AND UTILITY RESOURCES
- Adaptive phone equipment, including some emergency calling devices
- Bonding - rental discounts available in some cities for low income tenants
- Cable (some - for basic only)
- Call blocking services (various combinations are possible, at no charge)
- Department of Housing and Building Safety (various names in various cities); can help get landlords to make needed repairs
- ECIP (Emergency Crisis Intervention Program) 1-800-433-4327; provides emergency, one time only, payment of utility bills for people facing shut off. Also, can provide deposits for start-up service.
- Free “411” calls
- HEAP (Once a year assistance with utility bills at 1-800-433-4327)
- Home adaptation providers
- Housing insulation and repair programs, many for tenants as well as home owners
- Housing advocates, fair housing councils
- Legal Aid
- Lifeline rates and discounts (gas, electric, phone, water)
- Medical Baseline Discounts - increased allowance for lowest rate on utilities, based on necessary medical equipment (e.g., power wheelchairs, respirators)
- Newcomers Clubs
- Police (evictions, etc.)
- Waived or discounted deposit fees for utilities
- Welcome Wagons

* Developed by Jennifer Pittam, CHOICESS
Typical Generic Resources*

**MENTAL HEALTH SERVICES/CRISIS INTERVENTION**
- Battered women's shelters
- Church sponsored counseling services/programs
- Counseling centers
- County Department of Mental Health
- Crisis intervention teams
- Rape crisis centers
- Suicide hotlines
- Support groups around special issues
- Victim's of violent crime assistance programs

**MISCELLANEOUS**
- California Relay: Voice to TTD and TTD to voice for those with hearing impairments needing to receive/make calls to those without TTD equipment
- California Speech Relay: same idea as California Relay, designed for individuals whose speech is difficult for others to understand. 1-888-377-3324 (for info: 916-445-9692; Tom Burns)
- Centers for Applied Rehabilitation Technology
- City Hall
- Computer Access centers
- Discount camping fees at most state and federal parks
- Federal Information Center: 1-800-726-4995; can direct you to the correct federal resource to answer your question, request for information, etc.
- Free fishing licenses - State Department of Fish and Game
- Immigration / Refugee services
- Independent Living Centers
- Roommate Finders type services
- Senior centers / services
- State Information Office: 1-916-322-9900; can direct you to the correct state resource to answer your question, request for info, etc.
- Volunteer bureaus

**OTHER FINANCIAL RESOURCES**
- BOGG grants pay for registration costs at community colleges for people with low income.
- Consumer Credit Counseling
- Customer service representative at the bank
- Debtors Anonymous
- Dept. Of Public Social Services
- IHSS, AFDC, Food Stamps (Emergency), WIC
- F.E.M.A. (Federal Emergency Management Agency)

**PARENTING/FAMILY SUPPORT**
- Adoption/foster care services
- Childbirth preparation classes
- Child care referral services
- Head Start
- Legal aid
- Parenting classes
- Pregnancy help centers

**TRANSPORTATION**
- Carpool/Vanpool
- Discount transit vouchers - offered by the city to residents
- Driver training programs
- Para-transit companies
- Para-transit referral service
- Non-emergency medical transportation
- Taxi service

* Developed by Jennifer Pittam, CHOICESS
Information Brief

Generic Services

Introduction

Generic Resources are services typically funded by a government entity, complete with a set of eligibility criteria and regulations of their own. This section will cover the most common generic resources available to adults with developmental disabilities in California.

Department of Rehabilitation

The mission of the Department of Rehabilitation is to assist individuals with disabilities, emphasizing those with the most severe disabilities, toward informed choice and success in education, vocational training, career opportunities, independent living and in the use of assistive technology to improve their employment opportunities and their lives.

Once an employment goal has been determined, the Department of Rehabilitation (DR) counselor will work with the individual to develop a written plan (called the Individualized Written Rehabilitation Program or IWRP) for reaching that goal. DR’s rehabilitation services may include:

- counseling and guidance
- medical services and equipment
- additional assessment
- vocational training and education
- transportation assistance
- reader, interpreter, tutorial and notetaker services
- work tools, equipment and license fees
- personal assistance services
- self-employment services
- post-employment services
The Regional Center typically assists in the referral process to Department of Rehabilitation by providing the information needed to determine eligibility.

The Department of Rehabilitation also provides habilitation services that fund Work Activity Programs (long-term, sheltered work) and Supported Employment (community-based, integrated work) for individuals with developmental disabilities who are served by Regional Centers. The Habilitation Specialist reviews referrals made by the service coordinator and approves the development of an Individual Habilitation Plan (IHP) by a local DR service provider. The Habilitation Section is also responsible for follow along services for individuals in supported employment.

DR administers the California Assistive Technology System (CATS). They provide a toll-free information and referral number to answer any questions relating to assistive technology. Assistive technology is any devise that helps persons with disabilities perform work, education, social activities, daily living activities or anything else they want to do. CATS also coordinates loan guarantee programs to assist people who need modified vehicles, durable equipment, adaptive aids, or assistive devices.

DR is also responsible for planning, developing and funding Independent Living Centers (or ILCs). These centers are designed to assist people with disabilities in living fuller and freer lives outside institutions. The staff of an ILC are trained to assist people with disabilities to achieve economic and social independence. Services include peer counseling, advocacy, attendant referral, housing assistance, information and referral, transportation and training in independent living skills.

Disabled Student Centers

Consumers enrolled in college can enlist the assistance of the Disabled Student Center for help required to be successful in school. This might include help in getting around campus, notetakers, readers or other adaptations a student requires.

Food Stamp Program

The Food Stamp Program provides monthly benefits in the form of food stamps for low-income households. These benefits are part of the person's food budget for the month. Individuals who qualify for food stamps must: work for low wages, be unemployed or work part-time, receive welfare or other assistance program, be elderly or disabled and live on a small income, or be U.S. citizens or legal permanent aliens.

The food stamp office provides application forms on the same day of the visit. Interested individuals can ask for the application in person, over the phone, by mail or someone else may get one on his/her behalf.
Hill-Burton Free Care Program, County and Community Hospitals

Located by calling the Hotline (1/800/638-9742) to see which hospitals in your area may have a responsibility to provide free or low-cost health care as a “payback” for federal construction or modernization funds. Some hospitals have other funds for similar purposes. County and community hospitals have certain obligations to treat emergencies, whether the person can pay or not.

In-Home Supportive Services (IHSS)

IHSS provides personal care and domestic services to people who are aged, blind or disabled and who live in their own homes. To be eligible an individual must:

- be a lawful resident of California with low income and limited resources
- need IHSS care to remain safely in their own home

Individuals with disabilities can qualify for IHSS services, which might include meal preparation, laundry, shopping, nonmedical and other types of assistance. Eligibility for IHSS services is coordinated through the county Departments of Public Social Services. Authorized hours may range to a maximum of 283 hours per month, depending on the needs of the individual.

IHSS services which are allowable include:

- Domestic services (cleaning, changing linens, etc.)
- Related services (menu planning, shopping, etc.)
- Heavy cleaning services (due to special health problems, etc.)
- Nonmedical personal services (hygiene, grooming, ambulation, etc.)
- Medical transportation service
- Yard work services
- Protective supervision service (to protect against risk of injury / accident)
- Teaching and demonstration service
- Paramedical services under direction of health care professional (exercises, catheter care, injections, etc.)
Medi-Cal (State-federal Medicaid Program)

Serves low-income Californians who would otherwise not have access to medical/health care. About half the money is federal; half State. Medi-Cal covers a variety of services, when they are medically necessary. Recipients of Supplemental Security Income (SSI) are automatically eligible for Medi-Cal. Some others can qualify as medically needy, with a share-of-cost, if they have high medical expenses in any month. Besides primary, specialty (e.g., psychiatry; durable medical equipment) and acute care, the Medicaid program is used to fund a variety of other services and supports, some of which are described below. All told, over half of all funds for “developmental services” (including targeted case management; long-term health care in skilled nursing and intermediate care facilities; and waiver services) in California are financed through the Medicaid program.

California has applied for (and received) several Medicaid Waivers to provide Home and Community-Based Services (HCBS). Some are tied to intensive medical services and support where services can be provided as effectively and less expensively at home than within “an institution.” “Institution” includes many small, community facilities, not just hospitals, developmental centers and the like. Such services are used by some individuals with complex medical care needs, including being technologically-dependent for sustenance, breathing and the like. Other Medi-Cal funded services include (1) adult day health care (a day program option for some); (2) HCBS waiver services, such as personal care, so that more adults with developmental disabilities can live in their own homes (e.g., supported living services); and (3) even some supported employment services.

Medicare

A federally-funded, public health insurance program for the Nation’s elderly and selected others. It covers end-stage renal disease (e.g., kidney failure; transplantation) for people of all ages and in California SSDI recipients automatically have access to Medicare, regardless of age. Part A covers inpatient hospital care, care in a skilled nursing facility or hospice care. Part B covers the services of physicians and selected other professionals, outpatient hospital services, medical supplies and selected other services.

Mental Health Services

Physical medicine and mental health services have historically coexisted. Talk therapy and the use of various psychotropic medicines (to affect thinking and feeling) constitutes the domain of psychiatrists, psychologists, LCSW (Licensed Clinical Social Workers) and Marriage and Family Counselors. Some of these kinds of services, such as behavior management, are often provided through Regional Centers or the schools.

In an ideal world, “dually-diagnosed individuals,” meaning those with both developmental and psychiatric (or emotional) disabilities, would be treated collaboratively by those best positioned to make a positive difference. However, the mental health and developmental services
systems are organized differently. And, mental and physical health practitioners rarely work together. Some mental health practitioners (especially those who do talk therapy) feel that such services are a waste of effort for many people with cognitive impairments. At any rate, in approaching mental health professionals, one should focus on presenting symptoms (e.g., anxiety, depression, behavior) and not identify the person by a developmental disability label until the person’s foot is in the mental health door.

Public Transportation

The array of available and accessible public transportation services varies from area to area. Most individuals with developmental disabilities qualify for price reductions on bus passes to ride the public bus service. In addition, many communities operate a paratransit system (door-to-door van service) for people with disabilities who need to get to medical appointments and other community services. Check with the transportation coordinator or resource developer in your Regional Center for information about paratransit services and transportation discounts (e.g., bus passes, taxi vouchers).

Recreation

Most communities have a parks and recreation program. These programs offer a variety of sports, art instruction, classes, dance instruction, exercise, swimming, etc. Some park locations have adaptive equipment for people with disabilities as well. The programs are available to the public.

Section 8 Rental Assistance Program

The Section 8 Rental Assistance Program is federally-funded through the U.S. Department of Housing and Urban Affairs (HUD). Local housing authorities administer the program. The program provides a subsidy for renters who have low incomes. The program’s purpose is to provide low-income families (including families of one) with safe, decent and affordable housing.

Waiting lists are typically quite long: two or more years in most areas. Sign ups to be on the list may be only an occasional event. Some large cities provide publicly-owned housing (so-called “projects”). Increasingly, subsidies are provided through certificates and vouchers.

If accepted by a private-sector landlord for rent at or below fair market rent (FMR) for units of a given size (say, one-bedroom), a certificate means that the housing authority will pay the difference each month between the FMR and 30% of the family’s income. With a voucher, the family can rent units at rates above published FMRs, but the subsidy is the same as if the family
had a certificate. The renter pays extra — that is, the difference between what the landlord charges and FMR. Individuals who need round-the-clock attendant care typically will qualify for a two-bedroom unit on their own account.

Only a few local housing authorities have amended their HUD contracts to take advantage of the “shared housing option,” wherein more than one individual has exclusive right to a bedroom and shared use of common elements of the dwelling. One can sometimes move up on the waiting list if one can obtain preference points, which are given for each of the following: (a) paying over 50% of income for housing; (b) living in substandard housing; (c) being evicted.

Social Security (SSI, SSDI)

The Social Security Administration administers two programs of importance to many individuals with developmental disabilities: Social Security Disability Insurance (SSDI) and Supplemental Security Income/State Supplemental Payment (SSI/SSP). The former is all federal money; the latter is a combination of federal and state funds.

Social Security Disability Insurance (SSDI) is a social insurance program wherein a disabled individual receives a cash payment based on their own earnings record or that of a parent who has retired or died. There is no resource (or asset) test for receipt of SSDI. SSDI benefit levels depend on the earnings of the person on whose social security account the benefit is based, and on the number of persons drawing benefits on the same account. One must have a medically determinable disability expected to last 12 months or more that prevents substantial gainful activity (SGA). At present, the SGA criterion is $500 per month ($1,000, if blind). A person eligible for SSDI is also eligible for Medicare, with the premium for Part B services paid for the individual.

Supplemental Security Income/State Supplemental Payment (SSI/SSP) SSI/SSP is an income maintenance program for aged, blind, or disabled individuals (and couples) with low income and few resources. SGA is defined the same way as for SSDI. At present, “countable assets” (cash and near-cash) may not exceed $2,000 ($3,000 for a couple). Cash payments are not predicated on prior contributions to the Social Security Fund.

What about income from other sources? — One can receive $20 per month from any source (earned or unearned income) without experiencing a reduction in SSI/SSP. One can also earn up to $65 per month without a reduction in SSI/SSP. Beyond $85 in any month, however, earnings are “taxed” at 50 cents on the dollar. In other words, if a person would otherwise receive $650 per month in SSI/SSP, but has earnings of $185 in a month (and no other income from any other countable source), his or her SSI/SSP benefit would be reduced to $600 per month ($85 ignored; $50 reduction based on added $100 of earnings).
If adults with disabilities continue living with family — Children with disabilities who are living with their families, are often ineligible for SSI because of both family income and assets. But, once the person with a disability reaches age 18, he or she is considered a “family of one” and family assets and income no longer count against eligibility. Continued assistance from the family can, however, affect the amount of the monthly benefit. Hence, many families choose not to continue to provide food and lodging at no cost to the individual. Rather, they choose to keep records, and to “charge” their children fair market rent and their pro rata share of food, utilities and the like.

What assets are “countable”? What assets are ignored? — Countable assets include cash and near-cash (e.g., stocks, bonds). If countable assets exceed certain limits, SSI benefits may be terminated until those assets are spent down — that is, until any excess above the asset limit has been eliminated. Some assets are not countable (they are ignored). Such include a car (of limited value, unless used for work or medical appointments), a home in which the recipient is living, furnishings and clothing to a certain dollar amount, a small insurance policy and selected other assets (e.g., engagement ring and wedding band).

Are there ways of keeping more of one’s earnings or assets? — Yes, there are a set of “work incentives,” under Sections 1619(a) and (b) of the Social Security Act, that can be used. Being able to buy needed health insurance for awhile is one work incentive. Being able to claim certain “impairment-related work expenses” (IRWEs) against earnings can help. An approved “plan to achieve self-sufficiency” (PASS) can shelter some assets and earnings to buy work-related equipment (e.g., a specially equipped van; tools of a trade), to complete an educational program (e.g., bookkeeping certificate program), or to start a business.

Does where a person live matter for SSDI and SSI? — The answer is “Yes,” because residential services are funded in different ways. Services of ICF/DD-H and DD-N (Intermediate-care facilities/developmentally disabled-habilitative or nursing), for example, are charged to Medi-Cal. If the person is SSI-eligible, he or she will receive $42 per month for “personal and incidental needs,” nothing more. If a person lives in a licensed community-care facility, on the other hand, the person currently receives $796 per month in SSI/SSP, must turn over $703 to the residential service provider, and keeps $93 for “personal and incidental needs.” If a person lives “independently,” he or she will typically receive about $650 per month (more if no access to cooking facilities) and no distinction is made as to purpose. All is for the basics of food, clothing, shelter, and incidentals. (Another resource is SSI Questions and Answers for Persons Residing in Supported Living Arrangements, Department of Developmental Services, Adult and Supported Living Services, 1600 9th Street, Sacramento, CA 95814, 916-654-1956.)
Information Brief

Generic Housing Services

In your area are a number of generic housing services to consider when developing a pattern of support.

County Community Food and Housing Division

This service is typically made up of two programs: 1) Food Protection Program; and 2) Housing Program. The Housing program is responsible for enforcement of State Housing Codes. For example, they’re interested in substandard housing conditions due to lack of electricity, potable water, heat, natural light, ventilation, infestations of rodents or insects or a lack of connection to sewage disposal and structural hazards. These two services are usually a division of the local Department of Health Services.

Temporary Housing Services

You can usually find information on temporary housing through local community organizations such as a United Way Information Line or a Community Shelter service. Referrals for these services are typically made through a local human service agency, regional center, community service association, etc.

Public Housing

This is a program of U.S. Department of Housing and Urban Development (HUD) administered by County Housing Commissions. A rent supplement makes it possible for very low income families, senior citizens and persons with disabilities to live in city owned, managed or subsidized rental housing while paying no more than 30% of their income for rent. Resident screening for eligibility (income), credit references and past tenancies are also provided. Contact city or county housing authority for income levels and other information.

Shared Housing Programs

Local shared housing efforts match individuals with homeowners who want to reduce their cost of living, increase their expendable income and provide companionship and security. Information on shared housing is typically provided through local community service organizations (e.g., Catholic Social Services, Volunteer Center, Service Center for the Blind). You can typically find this housing support in a local service directory from the United Way or by looking under Social Services Organizations in the yellow pages.
General Information and Resources on Renting

There are a number of ways to get information about renting. For example, many counties have rental information and mediation services who provide handbooks on renter rights and responsibilities. In many areas, you’ll find a listing in the State Government Offices section of the phone book titled Homeowners and Renters Assistance for Senior Citizens and Disabled and Blind.

Utilities Services

Local Gas and Electric Companies offer programs for low income rate assistance. You can contact your local electric company for information on eligibility. Another program for low income customers is available through H.E.A.P. (Heat, Electricity, Available Program). The customer completes a form and the electric company determines amount of refund which should be made based on information. Contact your local utility for specific information.

Adaptive Telephone and Communication Services

Local phone company offers numerous programs such as:

1) Universal Lifeline. Offers low income customers substantial savings on telephone service. Eligibility is based on annual income, one phone number and not claimed as a dependent on another person’s tax return. Contact your local phone company for specific information.

2) Telephone equipment and services for people with physical impairments. Offers specialized communication equipment at no charge to make using the telephone easier for people who have physical limitations that interfere with hearing, speaking, seeing, dialing or holding a telephone. Many options are available. To qualify for services you need the following:

- have telephone service
- must be medically certified as disabled, or
- medically certified as "temporarily disabled"

Contact your local phone company's and ask for the Deaf and Disabled Services.
Teamwork and Diversity
Information Brief: Teamwork and Diversity

Diversity*

Definition of Diversity

Diversity is the important mixture of people who bring different backgrounds, styles, values, perspectives and beliefs as assets to the groups and teams with which they work.

Diversity and Work

We all have an opportunity to experience diversity in our lives every day. It may be diversity in age, ethnicity, nationality, religion, gender, ability or disability. Our openness to those experiences will determine whether we thrive in the diversity of the people we encounter or struggle with it.

It’s projected that by the year 2000, the majority of individuals with developmental disabilities in California will be non-white and non-Anglo. Even if you did not know this information, it just makes good sense to be as culturally aware as possible in your work.

What is It to Appreciate Diversity?

Sensitivity is the awareness of the feelings, values and attitudes of others. To be sensitive to and appreciate diversity, it’s important to:

- Let yourself try to experience life situations from the perspective of the individuals and families you support as well as your co-workers.
- Be aware of your own thoughts which might exaggerate and misinterpret the differences of individuals from another culture.
- Remember that, your role as a Supported Living Service Professional and team member is to support and respect the decisions of individuals and families.

*Cultural Sensitivity, prepared by Jose Hurtado, Eastern Los Angeles Regional Center (1996); Cultural Connection: Cross Cultural Competency Training, prepared by the Eastern Los Angeles Regional Center and the University of Southern California (1993).
Information Brief: Teamwork and Diversity

The Platinum Rule*

A good starting point for valuing and appreciating diversity is to view everyone as different from us, and to view them as people about whom we can’t make assumptions. Appearances are deceptive; people who appear to be very similar to us are often different, and those who appear to be very different can turn out to be quite similar.

The most important principle for valuing diversity is The Platinum Rule. This is an expansion of The Golden Rule. The Golden Rule is a time-honored practice that is a foundation of many religious disciplines. In telling us to "treat others as you want to be treated," its intentions are sound. It was designed to prevent us from doing harm to others – things which others obviously would not like.

With the increasing complexity of our society, we now need to extend The Golden Rule because it does not account for people's different and unique needs. We cannot assume that others want to be treated exactly the way we do. By assuming that everyone else wants what we do, we perpetuate the values and beliefs of the dominant culture. The Platinum Rule gives others permission to be different from us, and reminds us to honor that difference.

The Platinum Rule is:

Treat others as they want to be treated.

Using The Platinum Rule makes it okay for us to have differences. In the classic 1973 Harvard Business Review article, "What It's Like to Be a Black Manager," Edward Jones notes that removing the "taboo" of discussing differences is the first step toward valuing them.

The "fine line" of discussing differences is that they should be work related and behaviorally oriented. People should not feel they are being judged or labeled because of their differences.

Information Brief: Teamwork and Diversity

Diversity, Communication, and Teamwork*

Differences in Culture and Communication

There are some important differences in communication style that are influenced by culture. Here are some things to think about in communicating with individuals or families who are culturally different from you.

Eye Contact and Facial Expressions
Individuals with European cultural backgrounds (for example, English, German) usually appreciate eye contact. However, among many Asian cultures, eye contact between individuals who do not know each other is not appreciated and long periods of eye contact may be seen as not respectful.

Many individuals from European cultures show their emotions through expressions on the face (for example, lifting the eyebrow). However, individuals from Native American or Asian cultures may not communicate emotion through facial expressions unless they know someone well.

Closeness and Touching
Individuals from European cultures tend to stay a distance of about 3 feet, or an arm’s length, between themselves and others during conversations. However, individuals from Latin cultures are comfortable with closer conversational distances, while those from Asian cultures often prefer more space between the speaker and listener.

Among many Asian cultures, hugging, back slapping, and handshaking are not typical and should be avoided. Among some individuals from Middle Eastern cultures, use of the left hand to touch another person is a not okay because the left hand is used for personal hygiene.

Many individuals from European cultures show affection for children by patting them on the head. However, this is not an acceptable form of touch among many Asians who believe that the head is where the soul lives. Also, some East Indians believe that the head is fragile and should not be touched.

Gestures
Individuals from European cultures tend to use some gesturing while they talk as do some Latinos and Middle Easterners.

Nodding the head up and down is taken as a sign of understanding and agreement in many cultures, but among Asian, Native American, Middle

* Developing Cross-Cultural Competence, by Eleanor W. Lynch and Marc J. Hanson, Brookes Publishing (1992) and Regional Center Service Coordinator Orientation, Southern California Regional Center Director’s Association (1999).
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Eastern, and Pacific Island groups, it often only means, I hear you speaking. It does not mean that the person understands what is being said or agrees.

Also, individuals from European cultures often ask people to come their way by pointing with the index finger palm up and curling it toward the body while people from other cultures use this gesture only when summoning animals. In those cultures, it is never used with children or adults.

Good Communicators

Effective communication with individuals from other cultures works best when you:

• are flexible and can tolerate different points of view;

• make sincere attempts at trying to understand things from another point of view;

• are open to learning about another culture; and

• have a sense of humor.

Diversity and Teamwork

You will find diversity in the people you work with as well as the people you support. The information above about differences in culture and communication will also help you work as an effective team member. Teamwork is a key to successful service for people with developmental disabilities. In addition to the people you work with and support, your team will likely include family members, consultants, health professionals and regional center staff, as well as staff from other community services. So, it’s important to know some basics about teams and how they work best.

Some Team Basics

What is “teamwork”? Teamwork is about sharing, cooperating and helping one another. An effective team is a group of people working together with a common purpose who value each others contributions and are working toward a common goal. Working through teams usually gets better results than a lot of individual efforts which may be working against each other.

Many experts say trust is basic to successful teamwork. Trust takes time because it depends on people sizing up each other to see whether they say what they mean, do what they say and contribute to the work of the team.

Besides trust, other values that support teamwork are:

• open, honest communication;

• equal access to information; and

• focus on the goal.
Staying Healthy
Medications are powerful substances which many of us have come to depend on as an important part of our lives. Medications are substances taken into the body (or applied to) for the purpose of prevention, treatment, relief of symptoms or cure. Medications include the following:

- Prescription medications which must be ordered by a physician (or other person with authority to write prescriptions).
- Over-the-counter medications which can be purchased without a prescription.
- Vitamins, naturopathic remedies and homeopathic remedies are all medications.

Some Reasons Why Learning About Medications Is Important

Many medications do a lot of good. However, medications or drugs may also cause harm. Knowing about medications, their use and abuse and how to assist individuals in using them is vital to the health and well-being of those you serve.

Sometimes when a person takes a medication, it might make them feel confused, dizzy, anxious or cause change in one or more of the body functions (for example appetite, sleep, elimination). This is called an unwanted effect or side effect from the medicine. It is not uncommon for two or more medications to interact with one another causing an unwanted side effect.

In order for the physician to prescribe the best treatment and medication, he or she needs to be informed of the person's medical history, any drug allergies, current medications the person is taking and the purpose, medical and dental conditions and observations of recent physical or behavioral changes.

In addition, it is a good idea to get all prescriptions and over-the-counter medications at the same pharmacy or drug store so the pharmacist can maintain an active listing of all medications and check for potential drug-drug or food-drug interactions.

Consider the following:

✓ The Food and Drug Administration estimates that hospitalization resulting from inappropriate prescription drug use costs the nation $20 billion annually.
✓ Seventeen percent of hospitalizations of elderly Americans are the result of adverse side effects.

✓ Of the 2.3 billion prescriptions that are filled annually, approximately one half are not taken properly.

✓ Americans’ failure to take their medications as instructed costs more than $100 billion a year in increased hospital and nursing home admissions, lost worker productivity and premature death.

Abbreviations and Symbols Related to Medications Usage

A variety of abbreviations and symbols used by health care professionals that you may see and need to know are listed below:

q. (Q) = Every
Oz. = Ounce
d. = Day
tsp. = Teaspoon (or 5 ml.)
h. = Hour
Tbsp. = Tablespoon (3 tsp., or 15 ml.)
b.i.d. = Twice a day
gr. = grains
t.i.d. = Three times a day
mg. = milligrams
q.i.d. = Four times a day
GM, gm. = grams (1,000 mg.)
h.s. (HS) = Hour of sleep (bedtime)
Cap = Capsule
p.r.n. = when necessary, or as needed
Tab = Tablet
A.M. = Mornong
OTC = O ver-the-counter
P.M. = Afternoon/evening
Rx = Prescription
Qty = Quantity
Key Points When Assisting With Medications

In order to safely and effectively assist individuals with medications, you must:

• Assure that all medications are correctly self-administered.

• Watch carefully for adverse reactions and other side effects;

• Document changes in the illness or behavior, and in symptoms, adverse reactions, other side effects and apparent interactions in the individual’s record.

• Bring this information to the attention of appropriate persons (for example, the individual’s physician, other staff) in a timely manner and be sure it is acted upon.

• When accompanying a person on a physician visit, or getting a prescription filled, ask the physician and the pharmacist questions to get necessary information about the medication: what is the name of the medication; when to take it; what food or drinks should be avoided; and, are there any side effects?

• Read up on any medications being considered or prescribed.

Getting More Information (Books, Web Sites)

Most bookstores will have The PDR (Physician’s Desk Reference), which is the most comprehensive source of information on prescription drugs. It is fairly expensive ($75 - $100). There are a number of other excellent sources. Ask the individual’s physician or pharmacist to recommend one. Here are a few to consider:


http://www.intelihealth.com This is home for Johns Hopkins Health Information.

http://www.fda.gov This is the web site for the United States Food and Drug Administration.
Information Brief

Safe Practices When Handwashing

**Assemble Equipment:** Soap (bar or liquid), paper towels, warm running water, waste container.

Standing away from sink, turn on faucet and adjust water temperature. Keep your clothes dry moisture breeds bacteria.

Wet hands and wrists, keeping your hands lower than your elbows so water runs off your fingertips, not up your arm.

Use a generous amount of soap, rubbing hands together and fingers between each other to create a lather. Friction helps clean.

Continue to rub, push soap under your fingernails and cuticles with a brush or by working them in the palm of your hand. Use soap above your wrist about two inches. Wash for one minute.

Being careful not to touch the sink, rinse thoroughly under running water. Rinse from just above the wrists down to fingertips.

Do not run water over unwashed arm down to clean hands.

Using a clean paper towel, dry from tips of fingers up to clean wrists. Again, do not wipe towel on unwashed forearm and then wipe clean hands. Dispose of towel without touching waste container. If your hands ever touch the sink or waste container, start over.

Using a clean paper towel, turn off faucet, which is considered contaminated. Properly discard towel. Apply lotion if hands are dry or chapped.
Information Brief

Safe Practices When Using Gloves

Putting on non-sterile gloves

• Wash your hands following proper procedure.

• If you are right handed, remove one glove and slide it on your left hand (reverse, if left handed).

• Pulling out another glove with your gloved hand, slide the other hand into the glove.

• Interlace fingers to smooth out folds and create a comfortable fit.

• Carefully look for tears, holes or discolored spots and replace the glove if necessary.

• If wearing a gown, pull the cuff of the gloves over the sleeve of the gown.

Removing non-sterile gloves

• Touching only the outside of one glove, pull the first glove off by pulling down from the cuff.

• As the glove comes off your hand it should be turned inside out.

• With the fingertips of your gloved hand hold the glove you just removed. With your un gloved hand, reach two fingers inside the remaining glove, being careful not to touch any part of the outside.

• Pull down, turning this glove inside out and over the first glove as you remove it.

• You should be holding one glove from its clean inner side and the other glove should be inside it.

• Drop both gloves into the proper container.

• Wash your hands using proper procedure.
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Information Brief

Safe Practices When Lifting and Assisting Others

Lifting and Protecting One’s Back

At some time during their lives, four out of five people experience back problems (muscle spasms, slipped discs, etc.). Minimizing back problems calls for two things: (1) proper use of your body when lifting, pushing or reaching for things; and (2) exercises to strengthen your back. Regarding the former, it is a good idea to:

✓ Push, not pull (a garbage container; a dolly; a cart);
✓ Move, not reach (to get the things you need);
✓ Squat, not bend (when you have to reach down to get something); and
✓ Turn, not twist (when you want to go in a different direction).

The next page shows proper body mechanics when lifting, moving or reaching for things.

Helping with Transfers, Positioning

Helping individuals with impaired mobility

Individuals with greatly impaired mobility (for example, due to cerebral palsy, spinal cord injury, spina bifida and the like) need extra, more skillful support to remain comfortable and healthy.

• Hypertonus (spasticity) is too much muscle tone. Muscles become stiff and resist moving.
• Hypotonus is too little muscle tone, such that they have too little strength to move.
• Fluctuating muscle tone (athetosis or ataxia) involves unpredictable fluctuation from too much to too little tone. The movements appear uncontrollable.

Individuals need to be up as much as possible, rather than lying in a horizontal position. Gravity (2.2 pounds per square inch of body surface) plays havoc with body systems, especially respiratory, digestive and urinary. Disability stemming from immobility or lack of motion was identified in 1960, by the U.S. Public Health Service, as one of ten preventable health problems.1 Pneumonia,

Principles of Good Body Mechanics

**Keep the natural curve of the spine intact** A commonly recognized problem is lifting loads from the floor. But overhead loads can also be hazardous. It is better to build platforms to store loads off the floor (above knee height) to eliminate bending over, and to keep loads below shoulder height.

**Lift loads at about waist height** Ideally, loads should be at about waist height when lifted. For example, adjustable height stands can be used to raise pallets of boxes up and down to the right height (and also accommodate employees of varying heights).

**Eliminate twisting motions** Twisting motions, especially with a heavy load, place considerable stress on the spine. Improved layout is usually the best approach for eliminating this issue.

Reaching down into tubs and bins is a common source of back stress. Possible solutions include hydraulic tilters, springloaded bottoms and drop-down or removable sides.
osteoporosis (due to absence of weight bearing), gastro-esophageal reflux disease (GERD), and other conditions arise. Poor muscle tone often impacts chewing and swallowing. The person may push food out of the mouth; bite down forcefully on a metal utensil causing discomfort if not injury; or not be able to cough well enough to expel food or fluid that slips into the air pipe. Abnormal posture, combined with gravity, can make eating punishing. Pressure within the abdomen can rise; the normal opening in the diaphragm may be stretched; food (mixed with acid) may back up into the esophagus causing damage. Constipation, bowel obstruction and impaction are common, and often exacerbated by years of taking laxatives, seizure and other medication.

Positioning and movement

One should seek advice from an individual’s physician for any individual who needs help with positioning or mobility, so that ways of assisting are safe and effective. Typically, physical or occupational therapists are consultants for plans regarding an individual’s position or movement needs. If a person cannot change position on his/her own, someone must assist in repositioning. Because the absence of movement can result in discomfort and skin breakdown, someone needs to watch for places on the skin that are red or warm to touch. These are warning signs of skin breakdown. They should be written down in the individual’s record and brought to the attention of the individual’s physician.

Body mechanic principles

The North Dakota Center for Disabilities’ staff training module on “Positioning, Turning and Transferring” (1995, pp. 60-62) recommends these basic principles:

1. Do not lift loads heavier than those prescribed by your agency.
   Prior to lifting or moving an object or person, test the weight of the load to make sure it can be moved safely. Get help or use an assistive device if necessary.

2. Plan the move.
   Do not move the object any further than is absolutely necessary. Arrange the surface to which the object is to be moved as close as possible to the surface from which it is to be transferred. Provide firm, stable surfaces and, if possible, transfer between surfaces of equal height.

3. Use a wide, balanced stance with one foot ahead of the other.
   The solid base of support reduces the likelihood of slipping and jerking movements. Keep your feet flat on the floor and spread them about the width of your shoulders. Place one foot in the direction toward which you will move. This foot position gives you a wider base of support and allows a weight shift from one foot while maintaining your stability.

4. Keep the lower back in its normal, arched position while lifting.
   Bend at the knees or hips. With the back arched, the forces are more evenly distributed on the support structures.
5. **Bring the load as close to the body as possible.**
   Throughout the move, keep your arms and the object or person as close to your body as possible. This keeps your back from acting as the fulcrum and reduces the stress.

6. **Keep the head and shoulders up as the lifting motion begins.**
   This helps to keep the arch in the lower back.

7. **Tighten the stomach muscles as the lift begins.**
   This shifts some of the weight of the load from the spine to the abdominal cavity.

8. **Lift with the legs and stand up in a smooth, even motion.**
   Using the large, strong muscles of the legs to straighten the knees and hips as the lift is completed decreases the lower back stress. Use your whole body when pushing, pulling or lifting, not just your back and arms.

9. **Move the feet (pivot) if a direction change is necessary.**
   Throughout the move, your back, feet and trunk should all move together in the same direction, going to the same place. Avoid keeping your feet flat on the ground while twisting your body to move an object or person. When a turn is necessary, shift your feet and take small steps rather than twisting at the waist. Keep your feet pointed in the direction in which you are moving.

10. **Communicate if two or more individuals are involved in the movement.**
    This helps ensure the movement will be smooth, rather than sudden or jerking. It’s a good idea to count 1,2,3...with the person helping.

11. **Don’t lift when you can pull or push an object.**
    It’s safer and easier that way.

12. **Teach and preach.**
    Help fellow employees use the rules of good body mechanics.

**Some specific transfers and positioning guidelines**

Individuals vary in size, muscle tone and control of their bodies. They also have different needs with regard to help in moving about. Some people need help turning in bed. Some need help to sit up. Some need help in scooting forward or backward in a chair or bed. Some need help moving from bed to a chair, from a chair to the toilet, from a chair to bed, or from a chair (or bed) to the floor. Some need help walking from one place to another without falling. A plan (with whatever training is needed) should be devised for each person. Sometimes, a single helper can assist someone. Sometimes, two or more people may need to work together. Sometimes, mechanical aids (for example, lifting equipment) may be needed.
In general, helping people with positioning and transfers should attend to the following principles:

- Good planning;
- Asking the person how they want to be assisted;
- Encouraging as much participation as possible by the person being assisted;
- Using equipment (boards, sheets, lifts, etc.) when possible;
- Teaming up with another person when a two-person lift is needed; and
- Use of good body mechanics (good technique).

Wheelchair Safety

Wheelchairs are an example of adaptive equipment. Handrails, lifts, sliding seats (for example, into and out of the shower) and other devices are available to help with mobility and to reduce the risk of injury to both the person assisted and the person(s) assisting. Here are some guidelines for helping individuals who use wheelchairs:

- **Self mobilization:** Can the individual move themselves? If yes, encourage them to transport themselves as much as possible.
- **Individual sitting position:** Before starting check for the following:
  - Are the individual’s hips all the way back in the wheelchair?
- **Brakes:** Make sure that brakes are locked prior to assisting a person into or out of a wheelchair.
- **Holding on:** Grasp both push handles on the wheel chair firmly.
- **Starting and stopping:** Always start and stop slowly, take corners slowly and maintain a steady pace while moving. This is to avoid jostling the person or throwing him/her off balance.
- **Surface levels:** Be alert for changes in surface levels—for example, doorjambs or the floor of an elevator. Hitting a half inch rise at standard wheelchair speed can bend the front casters and pitch the person forward.
- **Opening doors:** Never open doors by pushing with the front of the wheelchair. This can damage the wheelchair’s footrests, the person’s feet, or the door. Stop the wheelchair, open the door by hand, and bring the wheelchair through. If the door does not stay open on its own, hold it with one hand or your backside. Do not let the door bang the side of the wheelchair.
- **Inclines and ramps:** The person’s weight should always be pushing
back toward you on inclines and ramps. Going uphill means pushing the person; to go downhill, turn the chair around and walk backwards. In this manner, the person’s weight will be pushing back toward you.

- **Outdoor surfaces**: Be alert for anything that can trap front casters or cause the wheelchair to tilt, such as holes, cracks, stones, sand or soft shoulders.

- **Curbs**: *Up curbs*—Stop at the curb, raise the front casters by pressing down on the foot lever, roll the front casters onto the sidewalk and roll the large wheels over the curb by lifting slightly on the push handles as you push forward. *Down curbs*—Always come down curbs facing backwards with the large wheels coming first. Maintain some upward pressure on the push handles as you pull the wheelchair toward you.

## Exercises to Strengthen Your Back

Anyone who lifts or moves people or objects around should do exercises to strengthen the back. However, be sure to check with your physician or other health care professional before starting the exercises shown on the next page.
Strengthening your entire body prevents future back problems and also improves your general health. Many exercises and sports strengthen your arms and legs. Doing special exercises to strengthen your abdominal muscles is also encouraged.

Keeping your body flexible helps you to use proper body mechanics that protect your back.

These exercises are not recommended for use during an acute back problem or spasm.

- If any exercise causes increased or continuing back pain, stop the exercise and try something else. Stop any exercise that causes the pain to radiate away from your spine into your buttocks or legs, either during or after the exercise.

- You do not need to do every exercise. Stick with the ones that help you most.

- Start with five repetitions three to four times a day, and gradually increase to 10 repetitions. Do all exercises slowly.

The basic types of exercises that can help your back include: flexion, extension, and stretching and strengthening.

**Flexion Exercises**
Flexion exercises stretch the low back muscles and strengthen the stomach muscles.

**Curl-Ups**
Curl-ups strengthen your abdominal muscles, which work with your back muscles to support your spine.

- Lie on your back with knees bent (60’ angle) and feet flat on the floor, arms crossed on your chest. Do not hook your feet under anything.

- Slowly curl your head and shoulders a few inches up until your shoulder blades barely rise from the floor. Keep your low back pressed to the floor. To avoid neck problems, remember to lift your shoulders and do not force your head up or forward. Hold for 5 to 10 seconds (do not hold your breath), then curl down very slowly.

**Pelvic Tilts**
This exercise gently moves the spine and stretches the low back.

- Lie on your back with knees bent and feet flat on the floor.

- Slowly tighten your stomach muscles and press your low back against the floor. Hold for 10 seconds (do not hold your breath). Slowly relax.

**Extension Exercises**
Extension exercises strengthen your low back muscles.
Press-Ups
Begin and end every set of exercises with a few press-ups (see illustration).

- Lie face down with hands at shoulders, palms flat on floor.
- Prop yourself up on your elbows, keeping lower half of body relaxed. If it’s comfortable, press your chest forward.
- Keep hips pressed to the floor. Feel the stretch in your low back.
- Lower upper body to the floor. Repeat 3 to 10 times, slowly.

Backward Bend
Practice the backward bend at least once a day, and do it frequently when working in a bentforward position.

- Stand upright with your feet slightly apart. Back up to a counter top for greater support and stability.
- Place your hands in the small of your back and gently bend backward. Keep your knees straight (not locked) and bend only at the waist.
- Hold the backward stretch for one to two seconds.

Strengthening and Stretching Exercises

Prone Buttocks Squeeze
This exercise strengthens the buttocks muscles, which support the back and aid in lifting with the legs.

- Lie flat on your stomach with your arms at your sides.
- Slowly tighten your buttocks muscles. Hold for 5 to 10 seconds (do not hold your breath). Slowly relax.
- You may need to place a small pillow under your stomach for comfort.

Hamstring Stretch
This stretches the muscles in the back of your thigh that allow you to bend your legs while keeping a natural curve in your back (see illustration).

- Lie on your back in a doorway with one leg through the doorway on the floor and the leg you want to stretch straight up with the heel resting on the wall next to the doorway.
- Keep the leg straight and slowly move your heel up the wall until you feel a gentle pull in the back of your thigh. Do not overstretch.
- Relax in that position for 30 seconds, then bend the knee to relieve the stretch. Repeat with the other leg.

Hip Flexor Stretch
This stretches the muscles in the front of your hip, which avoids "swayback" caused by tight hip muscles.

- Kneel on one knee with your other leg bent and foot in front of you. Keep a natural curve in your back.
- Slowly shift your weight onto your front foot, maintaining a natural curve in your back. Hold for 10 seconds. You should feel a stretch in the groin of the leg you are kneeling on. Repeat with the other leg.
Supported Living Services Training Tool Box

Part Three:
Information Briefs

Connections for Information and Resources on Community Living (CIRCL)

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