Taking Care of Your Adult Child with Intellectual/Developmental Disabilities

A brief guide to the healthcare benefits, legal options and helpful services available to parents taking care of their adult children with Intellectual/Developmental Disabilities
Bet Tzedek’s Transitions Project

Ensuring that your adult child is safe, healthy and living a meaningful life.

www.bettzedek.org
As the parent of a person with an intellectual/developmental disability (I/DD), you have been providing care, love, and support for your child over many years. As he or she ages, there are new challenges and issues ahead for both of you. Anticipating the changing needs of your adult child, and planning ahead for the future, will make life easier for everyone involved. The Transitions Project at Bet Tzedek recognizes those complex needs and, for the first time, is bringing together professionals, parents, and government agencies to create a coordinated system of care that addresses both aging and disability issues. This brochure will give you an overview of available services and resources.

Health Care Programs

**MEDI-CAL:** A California medical insurance program (called Medicaid in other states) that helps low-income individuals, families, seniors, and people with disabilities. It pays for hospitalization, medical visits, medical equipment/supplies, and prescription drugs as well as therapeutic services such as speech therapy, occupational therapy, and physical therapy. To be eligible, any income of the disabled adult can be counted separately from the rest of the family.

**MEDICARE:** A federal medical insurance program for those over 65 or who are disabled. Medicare pays for hospitalization, medical visits, medical equipment/supplies and some prescription drugs. Some people can qualify for both Medi-Cal and Medicare, and are sometimes referred to as “Dual Eligible.”

Financial Support

**IN-HOME SUPPORTIVE SERVICES (IHSS):** A California in-home care program for low-income people who are blind, disabled, or over 65 years old, administered by the Los Angeles County Department of Social Services. IHSS pays for daily home care services such as bathing, toileting, grooming, shopping, and cooking for those unable to care for themselves. The hours given are based on the recipient’s level of need with a cap on total hours, and can be used to pay for a family member providing services.
RESPITE CARE: Programs that provide money to pay for outside caregivers to give family members time off. Respite care is most often paid by the Regional Center if the adult child is eligible and qualifies for this service.

SOCIAL SECURITY/SSI: Federal programs that provide monthly payments to retirees starting at age 62 and also to severely disabled children and adults. To qualify your adult child with a disability, you will have to provide documentation that shows that the condition results in the inability to engage in any type of work and which has lasted or can be expected to last for at least a year. No benefits are payable for partial disability or for short-term disability.

Call (toll-free) 800-772-1213, 7 a.m. to 7 p.m., Monday through Friday or go to www.ssa.gov/disability/disability_starter_kits_adult_eng.htm.

Legal Issues

LIMITED CONSERVATORSHIP: When your child turns 18, he or she becomes an adult and legally has the right to make his or her own decisions. If he or she lacks the capacity to make decisions, you may consider petitioning the Probate Court for a Limited Conservatorship. This would give you (the conservator) the authority to make personal and financial decisions for your adult child (the conservatee), including decisions about:

1) Where he or she will live (Locked facilities are not an option)
2) Access to confidential records and documents
3) The right to enter legal contracts
4) Consent for medical decisions (Sterilization is not included)
5) Education or job training
6) Determine appropriate social and sexual contacts
7) Consent to marriage
In return for the court granting these powers, the conservator has the responsibility to get the treatment, services, and opportunities to help the conservatee to achieve maximum independence.

If you are interested in learning more about obtaining a limited conservatorship for your adult child over the age of 18, go to www.bettzedek.org/our-services/aging-with-dignity or call Bet Tzedek at 323-939-0506.

**POWER OF ATTORNEY FOR HEALTH CARE:** A high-functioning adult with developmental disabilities can choose to appoint parents or other relatives to speak on his or her behalf with medical providers. It can also list specific health care instructions.

**DURABLE POWER OF ATTORNEY FOR FINANCES:** Similar to the above, but for legal and financial decisions such as paying bills or signing contracts.

**REPRESENTATIVE PAYEE:** This is a person who helps another person manage SSI or Social Security Checks. The representative payee can be a family member, non-profit agency, friend, or Regional Center Service Coordinator.
Support, Employment and Housing

OVERALL SUPPORT/COORDINATION

REGIONAL CENTERS: If your adult child with I/DD is part of a Regional Center, you should be speaking regularly with your appointed Service Coordinator and participating in an annual IPP (Individual Person Planning). Your adult child should be part of these meetings.

If your adult child with I/DD has never been part of a Regional Center, or been denied services, please contact Disability Rights California (toll-free) at 800-776-5746 (Voice) or 800-719-5798 (TTY) or go to www.disabilityrightsca.org.

EMPLOYMENT

The California Department of Rehabilitation provides services and advocacy for employment, independent living, and equality for individuals with less severe disabilities.

In Los Angeles County, you can visit one of seven offices: www.rehab.cahwnet.gov/dor-locations/code/county.asp?county=Los-Angeles or call (toll-free) 800-952-5544 (Voice), 866-712-1085 (TTY).

FOR PERSONS WITH MORE SIGNIFICANT DISABILITIES, there is The Work Services Program from the California Department of Developmental Disabilities, which provides work and community integration opportunities through Supported Employment Programs (SEPs) and Work Activity Programs (WAPs). These programs are available to persons who are Regional Center clients only. For more information go to www.dds.ca.gov/ConsumerCorner/EmployFamResources.cfm or call 916-654-1690 (Voice) or 916-654-2054 (TTY).

ADDITIONAL EMPLOYMENT OPPORTUNITIES ARE AVAILABLE FROM:

- Best Buddies CA: www.bestbuddiescalifornia.org
- The ARC: www.arcaselac.org/employment_services.html
- Easter Seals: www.southerncal.easterseals.com
- Goodwill Industries: www.goodwillsocal.org
- TASC (Adult Skills Center): www.taschq.com
- Tierra del Sol Foundation: www.tierradelsol.org or 818-352-1419
There are a variety of housing options for adults with developmental disabilities including:

1) **COMMUNITY CARE FACILITIES** (often referred to as “group homes”), are licensed by the State of California. These facilities (3 to 6 people depending on the level of care) provide 24-hour, non-medical care to children and adults who need personal services, supervision, and/or assistance essential for safety or everyday activities. There are four levels of care depending on the needs of the person. [www.dds.ca.gov/LivingArrang/CCF.cfm](http://www.dds.ca.gov/LivingArrang/CCF.cfm)

2) **INDEPENDENT LIVING PROGRAMS** are supervised by regional centers, and they provide or coordinate support services for individuals in independent living settings. They focus on training adults how to take care of themselves and, for people with physical disabilities, aides can be hired to assist them in meeting their personal needs. [www.supportedliving.com/index.html](http://www.supportedliving.com/index.html)

3) **FAMILY HOME AGENCIES (FHA)** is a new option which matches developmentally disabled adults with host families to promote self-determination and interdependence. These are family homes for up to two adults with developmental disabilities who live with a family outside of their own family home. Contact your local Regional Center for more information.

4) **ASSISTED LIVING** is designed for seniors that require some assistance with everyday tasks such as dressing and bathing but also wish to live as independently as possible. Assisted living is appropriate for someone who is too frail to live at home or in an independent setting but does not need skilled nursing care. For adults over age 59 only: [www.calregistry.com/index.htm](http://www.calregistry.com/index.htm)
The Transitions Project, an initiative of Bet Tzedek Legal Services, is designed to address and develop coordinated, holistic care for adults over the age of 30 with intellectual/developmental disabilities and their aging family caregivers.

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For more information, visit: www.bettzedek.org