

This is a list of websites, books, and publications that will lead to support for parents who have children with special healthcare needs. This is not an exhaustive list, but a list that includes organizations that are parent-run or lead and are family-centered. In addition, the links are current at time of site publication. If the link does not work, use Google (or another search engine) to find the organization named.

## Resources for Families with Children with Special Healthcare Needs

### *Websites*

<http://familyvoicesofca.org>

Family Voices of California (FVCA) is a statewide collaborative of locally-based parent run centers working to ensure quality health care for children and youth with special health care needs.

<http://kidshealth.org/parent/>

If you're looking for information you can trust about kids and teens that's free of "doctor speak," KidsHealth is the most-visited site on the Web for information about health, behavior, and development from before birth through the teen years.

<http://www.nlm.nih.gov/medlineplus/>

MedlinePlus is the National Institutes of Health's Web site for patients and their families and friends. Produced by the National Library of Medicine, it brings you information about diseases, conditions, and wellness issues in a language you can understand. MedlinePlus offers reliable, up-to-date health information, anytime, anywhere, and for free.

<http://www.disabilityrightsca.org/pubs/547001Index.htm>

IHSS (In-home Support Services) is a program for seniors & individuals with disability to have paid assistance at home, primarily to prevent hospitalization and increase safety.

<http://www.100percentcampaign.org/>

This is a website developed by several agencies who work together to ensure that all of California's children gain access to affordable, comprehensive health coverage. Website has information about healthcare insurance.

<http://www.myspinabifidabook.org/>

This website contains a book that can be read or heard online regarding a young child with spina bifida. In addition, there are links to activities and information about nutrition.

<http://www.rarediseases.org/>

The National Organization for Rare Disorders (NORD)

<http://www.geneticalliance.org/resources>

Information about resources for children and adults with genetic conditions

<http://chromodisorder.org>

Chromosome Disorder Outreach, Inc. is a non-profit organization, founded, supported, and run by parents just like you. Our children are affected by a wide range of chromosome disorders, including deletions, duplications, trisomies, inversions, translocations, and rings. Sometimes these disorders are so unusual that doctors tell us, "You're the only one out there."

[http://www.uscucedd.org/index.php?option=com\\_content&view=article&id=65&Itemid=216](http://www.uscucedd.org/index.php?option=com_content&view=article&id=65&Itemid=216)

USC University Center for Excellence on Developmental Disability is one of the Centers in California located with USC and providing technical assistance and referral to parents around medical and developmental issues

<http://www.cdc.gov/ncbddd/disabilityandhealth/index.html>

CDC.gov provides users with credible, reliable health information

<http://www.ssa.gov/pubs/10026.html#ssi-benefits>

Social Security Benefits for Children is a financial assistance program for families with children with disabilities,

[http://brightfutures.aap.org/Family\\_Resources.html](http://brightfutures.aap.org/Family_Resources.html)

Bright Futures materials for families are available on a wide range of mental, physical, and emotional health issues for children from the prenatal months through age 21.

<http://www.healthychildren.org/english/ages-stages/Pages/default.aspx>

This website will give you information on developmental stages of your child and information to assist you with your child's health care concerns.

[www.readyssetgrowla.org](http://www.readyssetgrowla.org)

This is a website provided by First 5 LA for parents including resources for parents and activities for kids in throughout LA County.

<http://www.dds.ca.gov/>

The California Department of Developmental Services is the agency through which the State of California provides services and supports to individuals with [developmental disabilities](#). Check out the consumer corner and their publications. There are some very good publications about visioning for the future and planning for inclusion.

<http://ras-pathway-syndromes.com>

Rasopathies Network USA is a resource a repository for research on syndromes with mutations onf the Ras/MAPK signaling pathway

[www.bravekids.com](http://www.bravekids.com)

An on-line resource center for children with disabilities or chronic/ life threatening illnesses that provides over 11,000 resources, medical information and emotional support for children with special needs such as autism, cancer, cerebral palsy, ADD & many more

<http://low-vision.org/>

The Center for Partially Sighted is an agency that provides information and support on low vision.

<http://www.clubtwentyone.org/>

Club 21 seeks to become a vital link in every family and educator's support network, offering services to children of all ages while helping them become visible, active, and appreciated members of the community

*Newsletters:*

Deaf-Blind Perspectives is a free publication, published two times a year by the National consortium on Deaf-Blindness. Paper copies are available free of charge to subscribers within the United States. E-mail subscriptions are available (Ascii text only). All issues are available online at <http://nationaldb.org/dbp> or call Randy Klumph (503) 838-8885, TTY (503) 838-8821