



Accessing Services Directory and Curriculum Glossary

For 316 - Meeting the Needs of Medically Complex Children

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Developed by:
SUN Home Health Services, Inc.
David Hoffman, B.S.N., R.N.
Donna Jenkins, B.S.N., R.N.C.
Maureen Conlon-Drepps, M.S.N., R.N.C.
Joan Mosier, M.P.A.

Help Resources

Toys and Adaptive Equipment

1. Able Ware Catalog
Maddak, Inc.
Pequannock, NJ 07440-1993

Mobility, Positioning, Communication, seating, wheelchair accessories, grooming, therapeutic games, language and speech, treatment and activities
2. Achievement Products, Inc.
P.O. Box 9033
Canton, OH

Phone: 1-800-373-4699

Fax: 1-330-453-0222

Positioning, Furniture, Mobility, Ambulation, Gross Motor, Early Stimulation, Perceptual Development
3. Dynavox 2
Augmentative Communication Device

Phone: 1-800-344-1778
4. Flaghouse, Inc.
601 Flaghouse Drive
Hasbrouck Heights, NJ 07604-3116

Phone: 1-800-793-7900

Internet – <http://www.flaghouse.com>

Gross Motor, Ride Ons, Active Play, Board Games, Living Aids, Adapted Toys, Sound and Music, Sensory Stimulation
5. Ford Mobility Motoring Program
Motor Vehicle Adaption

Phone: 1-800-952-2248
6. Protecta Cap
Protective Head Gear
Plum Enterprises, Inc.
9 Clyston Circle
P.O. Box 283
Worcester, PA 19490

Phone: (610) 584-5003
7. Scooters

Able Data
8455 Colesville Rt.
STE. 935
Silver Springs, MD 20910-3319

Phone: 1-800-227-0216

8. Smith and Nephew, Inc.
One Quality Drive
P.O. Box 1005
Germantown, WI 53022-8205

Phone: 1-800-558-8633

Fax: 1-800-545-7758

Ambulation Aids, transfer boards, wheelchair aids, leisure activities, splints, eating utensils, cognitive – perceptual motor products

9. Step 'N Go
Treadle Power, Inc.
P.O. Box 180
189 Field's Farm Road
Charlotte, VT 05445

Treadle Power Platform Bicycle

CASSETTE BOOKS/DISC/BRAILLE/MAGAZINE

1. **National Library Service**
For the Blind and Physically Handicapped
Library of Congress
Washington, DC 20542

Children's Selections, Spanish, Young Adult, Magazines
2. **Spinoza™ . . . The Bear Who Speaks From The Heart**

245 East 6th Street
St. Paul, MN 55101-1940

Phone: (612) 227-3717
or 1-800-CUB-BEAR
3. **Exceptional Parent**
The Magazine for Parenting a Child with a Disability

Phone: 1-800-247-8080

HOME HEALTH CARE/VISITING NURSES

1. **Pennsylvania Association of Home Health Agencies**
20 Erford Road, Suite 115
Lemoyne, PA 17043

Phone: (717) 975-9448
1-800-382-1211 (inside PA)

2. **SUN Home Health Services, Inc.**
Central Pennsylvania's Visiting Nurse Association
61 Duke Street, P.O. Box 232
Northumberland, PA 17857

Phone: 1-888-4-SUNcare (1-888-478-6227)



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HOSPICE

1. **Pennsylvania Hospice Network**
P.O. Box 60636
Harrisburg, PA 17106-0636

Phone: (717) 230-9993

2. **SUN Home Hospice**
61 Duke Street, P.O. Box 232
Northumberland, PA 17857

Phone: 1-888-4-SUNcare (1-888-478-6227)



INTERPRETING SERVICE

Language line services provide a telephone interpreter on the telephone whenever you need to communicate with a non-English speaker: 24-hours/day – 7 days/week.

Call 1-800-996-8808 for enrollment information or one-time use.

DISEASE SPECIFIC RESOURCES

AIDS

Caring for Someone with AIDS at Home is a guide to help caregivers prepare to care for a person with AIDS in the home care setting. It discusses stress management information, common misconceptions about the spread of AIDS, and topics and problems that caregivers may not expect (such as bedsores, food preparation, and emotional support to the patient). The glossary provides simple definitions of many terms associated with AIDS. In addition, the section entitled "Places to Call for Help" is invaluable, offering various hotline information and toll-free numbers of organizations that offer assistance.

To order Caring for Someone with AIDS at Home, call the CDC National AIDS Clearinghouse at (800) 458-5231.

American Cancer Society

90 Park Avenue
New York, NY 10017

Phone: (800) -227-2345 (Pennsylvania)

The American Cancer Society is a voluntary organization that offers a variety of patient services, including publications, videos, and sponsorship of the support programs. ACS local units are organized to cover all counties in Pennsylvania. Limited financial services are available to cancer patients.

American Diabetes Association

Diabetes Information Service Center
1 660 Duke Street
Alexandria, VA 22314

Phone: (703) 549-1500

American Heart Association

American Heart Association National Center
7272 Greenville Avenue
Dallas, TX 75231

Phone: (214) 373-6300

The mission of the American Heart Association is to reduce disability and death from cardiovascular diseases and stroke.

To make contact with the office closest to you, check your telephone book or contact your area American Heart Association district office. These are located in Wilkes-Barre, Williamsport, Erie, Lancaster, and Pittsburgh.

Aplastic Anemia

Aplastic Anemia Foundation of America

P.O. Box 613
Annapolis, MD 21404

Phone: (800) 747-2820
e-mail: aafacenter@aol.com

The Aplastic Anemia Foundation of America (AAFA) serves as a resource for patient assistance and emotional support and provides educational materials and updated medical information on aplastic anemia and other forms of bone marrow failure such as myelodysplastic syndrome.

Autism

Autism Society of America
7910 Woodmont Avenue
Suite 650
Bethesda, MD 20814

Phone: (800) 3-AUTISM

Cancer Information Service

The National Cancer Institute
Bethesda, MD 20892

Phone: (800) 422-6237

The National Cancer Institute is an agency of the National Institutes of Health, U.S. Department of Health and Human Services. Its Cancer Information Service, open 7 days a week, is staffed by trained persons who can answer your questions regarding cancer, medical facilities, home care assistance program, financial aid, emotional counseling, and other services. They also can send you relevant information about specific types of cancer.

Celiac Sprue

Celiac Sprue Association/USA Inc.,
Leon H. Rottmann, Ph.D, Executive Director
P.O. Box 31700
Omaha, NE 68131-0700

Phone: (402) 558-0600

Celiac Sprue is a malabsorption problem precipitated by ingestion of gluten-containing foods.

Cerebral Palsy

United Cerebral Palsy Association
710 Penn Plaza – Suite 804
New York, NY 10001

Phone: 1-800-USA-IUCP

CH.A.D.D. (Children and Adults with Attention Deficit Disorder)

499 NW 70th Avenue, Suite 101
Plantation, FL 33317

Phone: 1-954-587-3700

e-mail: <http://www.chadd.org/>

fax: 1-954-587-4599

Hemochromatosis

Hemochromatosis Foundation
P.O. Box 8569
Albany, NY 12208

Phone: (518) 489-0972

Hemochromatosis is a genetic iron-loading disorder from infancy on, and slowly accumulates in the body. Undetected, the accumulating iron will damage vital organs and joints. Treatment can not only prevent organ damage, but also can reverse damage if not too advanced. For information send a \$.55 self-addressed, stamped envelope to the above address.

Hepatitis

American Liver Foundation
1425 Pompton Avenue, Cedar Grove, NJ 07009

Phone: (800) GO-LIVER

Or: (201) 256-2550

The American Liver Foundation is dedicated to treating, curing and preventing liver diseases through research and education.

Kidney

American Association of Kidney Patients
1000 S. Ashley Drive, Suite 280
Tampa, FL 33602

National Kidney Foundation, Inc.
30 E. 33rd Street
New York, NY 10016

Phone: (800) 622-9010

Leukemia

Leukemia Society of America
Marketing and Communications Department
600 Third Avenue
New York, NY 10016

Phone: (800) 955-4LSA

Or (212) 573-8484

Lupus

Lupus Foundation of America (LFA)
Four Research Place, Suite 180
Rockville, MD 20850-3226

Phone: (800) 558-0121

Or: (301) 670-9292

Fax: (301) 670-9486

Mental Health

Division of Public Affairs
American Psychiatric Association
1400 K Street NW
Washington, DC 20005

Muscular Atrophy

Sherry Colander or Sue Schneider
Families of Spinal Muscular Atrophy
P.O. Box 196
Libertyville, IL 60048-0196

Phone: (800) 886-1762

Families of Spinal Muscular Atrophy (SMA) provides information on the diseases, telephone support, newsletter, videotape and parent to parent contact referrals and promotes public awareness.

Movement Disorders

Illinois Chapter of American Academy of Pediatrics
Pathways Awareness Foundation
123 North Wacker Drive
Chicago, IL 60606

Phone: (800) 955-CHILD

Ostomy

United Ostomy Association
36 Executive Park
Suite 120
Irvine, CA 92714

Phone: (800) 826-0826

Or (714) 660-9262

Fax: (714) 660-8624

The United Ostomy Association is a voluntary health agency dedicated to the rehabilitation of people who have had ostomy surgery.

Scleroderma

United Scleroderma Foundation, Inc.
P.O. Box 399
Watsonville, CA 95077-0399

Phone: (800) 722-HOPE

Or: (408) 728-2202

SIDS (Sudden Infant Death Syndrome)

National Sudden Infant Death Syndrome Foundation

Phone: (800) 331-5105

Back to Sleep Campaign

P.O. Box 29111
Washington, D.C. 20040

Phone: (800) 505-CRIB

SIDS Alliance

Phipps Cohe
National Public Affairs Director
1314 Bedford Avenue
Suite 210
Baltimore, MD 21208

Phone: (800) 221-SIDS (7437)

Fax: (410) 653-8709

Association of SIDS Program Professionals

Massachusetts Center for SIDS
Boston City Hospital
818 Harrison Avenue
Boston, MA 02118

Phone: (617) 534-SIDS

Sickle Cell Disease

Ralph D. Sutton, Deputy Director
Sickle Cell Disease Association of America
200 Corporate Pointe
Suite 495
Culver City, CA 90230

Phone: (800) 421-8453

Spina Bifida

Spina Bifida Association of America
4590 MacArthur Boulevard
Suite 250
Washington DC 20007-4226

Phone: (202) 944-3285

Spina bifida is the most frequently occurring permanently disabling birth defect.

Wegener's Granulomatosis

Wegener's Granulomatosis Support Group, Inc.
P.O. Box 1518
Platte City, MO 64079-1518

Phone: (800) 277-WGSG (9474)
Or (816) 858-4088

Fax: (816) 858-4444

Wegener's Granulomatosis is an uncommon inflammatory disease involving the respiratory tract and kidneys as well as other major organs.

Other**Brain Injury**

Brain Injury Association
1776 Massachusetts Avenue NW
Suite 100
Washington DC 20036

Phone: (202) 296-6443

Fax: (202) 296-8850

Nearly two million Americans sustain brain injuries each year – one fourth of these injuries are severe enough to require hospital admission. With one brain injury occurring every 15 seconds, this national health concern ranks as the leading cause of death and disability in children and young adults.

Choice In Dying, Incorporated

250 West 57th Street
New York, NY 10107

Phone (212) 366-5540

Choice In Dying, Inc., is the national council for the right to die. This nonprofit educational organization distributes information on advance medical directives, provides psychological and legal counseling, and makes referrals to local organizations.

Feeding:

Child Assessment Feeding Scale
Georginia Sumner, Director CAFS
University of Washington
Seattle, WA

Phone: (206) 543-8526

Hearing Aide

International Hearing Society
203 61 Middlebet Road
Livonia, MI 48152

Phone: (800) 521-5247

Fax: (810) 478-4520

Make-a-Wish Foundation of America

Suite 205
4601 North 16th Street
Phoenix, AZ 85016

The Make-a-Wish Foundation of America works closely with families of terminally ill children (up to age 18). It works with families to cover expenses and to arrange for granting a child's special wish, which will provide encouragement, respite and special memories.

Medic Alert

Medic Alert
2323 Colorado Avenue
Turlock, CA 95381-1009

Phone: (800) ID ALERT (432-5378)

Since 1956, Medic Alert, a nonprofit, charitable foundation, has offered emergency medical identification services, which include an alerting emblem on a bracelet or necklace, individually engraved with patient vital medical facts and the 24-hour emergency hotline phone number for computerized information, plus a frequently updated wallet card with medical and personal information. Initial membership is \$35 for all services, including the emblem and chain, followed by an annual fee of \$15.

Rehabilitation

Rehabilitation Resource Center
c/o Medical Education Institute, Inc.
585 Science Drive, Suite B
Madison, WI 53711

Phone: (800) 468-7777

Stuttering

Stuttering Foundation of America
P.O. Box 11749
Memphis, TN 38111-0749

Phone: (800) 992-9392

Resource

“Children with Special Health Needs: A Resource Guide”, August, 1993

Published by National Center for Education in Maternal & Child Health, Arlington, VA
Single copies available at no cost from:

National Maternal and Child Health Clearinghouse
8201 Greensboro Drive, Suite 600
McLean, VA 22102

Phone: (703) 821-8955, extension 254 or 265

Fax: (703) 821-2098

Contains an overview of programs for children with special health needs, publications and resource materials, and listings of national organizations.

Resource Guide NMCHC Order Form

<input type="checkbox"/> C019 – Johnson, B.H., McGonigel, M.J., and Kaufman, R.K. (Eds.). (1989). Guidelines and recommended practices for the individualized family service plan.	<input type="checkbox"/> B3490 – National Center for Education in Maternal and Child Health. (1988). Starting early: A guide to federal resources in maternal and child health.
<input type="checkbox"/> C110 – Meisels, S.J., and Provence, S. (1989). Screening and assessment: Guidelines for identifying young disabled and developmentally vulnerable children & their families.	<input type="checkbox"/> B118 – U.S. Department of Health and Human Services, Division of Maternal and Child Health. (1982). Report of the Surgeon General's workshop on children with handicaps and their families – Case example: The ventilator – dependent child.
<input type="checkbox"/> C077 – Anderson, P.P., and Fenichel, E. S. (1989). Serving culturally diverse families of infants and toddlers with disabilities.	<input type="checkbox"/> B313 – U.S. Department of Health and Human Services, Public Health Service. (1987). Surgeon General's report: Children with special health care needs – Campaign '87.
<input type="checkbox"/> G017 – Bishop, K.K., Woll, J., and Arango, P. (1993). Family/professional collaboration for children with special health needs and their families.	<input type="checkbox"/> E016 – Tluczek, A., and Sondel, S. (1991). Project SPOON: Special program of oral nutrition for children with special needs.
<input type="checkbox"/> F061 – National Maternal and Child Health Resource Center. (n.d.). A national goal: Building service delivery systems for children with special health care needs and their families – Family centered community based coordinated care.	<input type="checkbox"/> F063 – May, J. (1992). Circles of care and understanding: Support programs for fathers of children with special needs.
<input type="checkbox"/> E013 – National Center for Education in Maternal and Child Health. (1991). Maternal and Child Health Bureau active projects. FY 1991: An annotated listing.	<input type="checkbox"/> F068 – U.S. Department of Health and Human Services, Maternal and Child Health Bureau. (1992). Moving on: Transition from child-centered to adult health care for youth with disabilities.

To obtain one free copy of any of the titles above please complete this order form and return to:

National Center for Education in Maternal and Child Health
2000 15th Street North, Suite 701
Arlington, VA 22201-2617
(701) 524-7802

Name: _____

Position: _____

Organization: _____

Address: _____

City: _____ State: _____ Zip: _____

Telephone number: _____

Early Intervention Program

For more information on the early intervention program available in your county, contact the appropriate Mental Health/Mental Retardation (MHMR) Office.

Allegheny	Allegheny County MH/MR/D&A/H&H Program Wood Street Commons 304 Wood Street Pittsburgh, PA 15222 (412) 350-4457
Armstrong/Indiana	Armstrong/Indiana County MH/MR Program Armsdale Administration Building RD 8, Box 293 Kittanning, PA 16201 (412) 548-3451
Beaver	Beaver County MH/MR Program 148 Theodore Drive Beaver Falls, PA 15010 (412) 847-6225
Bedford/Somerset	Bedford/Somerset MH/MR Program 245 West Race Street Somerset, PA 15501 (814) 443-4891
Berks	Berks County MH/MR Program 633 Court Street, Department 504 Reading, PA 19601-4301 (610) 478-4900
Blair	Blair County MH/MR/D&A Program 222 Lakemont Park Boulevard Altoona, PA 16602 (814) 942-7888
Bradford/Sullivan	Bradford/Sullivan MH/MR Program RD 1, Box 179A Towanda, PA 18848 (717) 265-2211 or (800) 588-1828
Bucks	Bucks County MH/MR Department 600 Louis Drive, Suite 101 Warminster, PA 18974 (215) 442-0760
Butler	Butler County MH/MR/D&A Programs 124 West Diamond Street, 2 nd Floor County Government Center Post Office Box 1208 Butler, PA 16003-1208 (412) 284-5114

Cambria	Cambria County MH/MR/D&A Programs 131 Market Street Johnsonburg, PA 15901 (814) 535-8531
Cameron/Elk/McKean	Cameron/Elk/McKean MH/MR Program Seneca Building 2 Main Street Bradford, PA 16701 (814) 362-4601
Carbon/Monroe/Pike	Carbon/Monroe/Pike MH/MR Program 720 Phillips Street Stroudsburg, PA 18360 (717) 420-1900
Centre	Centre County MH/MR Program Willowbank Office Building 420 Holmes Street Bellefonte, PA 16823 (814) 355-6782
Chester	Chester County Department of MH/MR Government Services Center 601 Westtown Road – Suite 340 West Chester, PA 19382-4524 (610) 344-6265
Clarion	Clarion County MH/MR/D&A Programs 214 South Seventh Avenue Clarion, PA 16214 (814) 226-5840
Clearfield/Jefferson	Clearfield/Jefferson MH/MR Program 1200 Wood Street – Suite U 110 Brockway, PA 15824 (814) 265-1060
Columbia/Montour/ Snyder/Union (CMSU)	CMSU MH/MR Program Post Office Box 219 Danville, PA 17821 (717) 275-5422
Crawford	Crawford County MH/MR Program 628 Arch Street Suite B-101 Meadville, PA 16335 (814) 336-4352
Cumberland/Perry	Cumberland/Perry MH/MR Program Human Services Building, Suite 301 16 West High Street Carlisle, PA 17013 (717) 240-6320

Dauphin	Dauphin County MH/MR Program Dauphin County Human Services Building 25 South Front Street Harrisburg, PA 17101 (717) 255-2890
Delaware	Delaware County Human Services 20 South 69 th Street, Fourth Floor Upper Darby, PA 19082 (610) 713-2326
Erie	Erie County MH/MR Program 154 West Ninth Street Erie, PA 16501-1303 (814) 451-6800 or (814) 451-6860
Fayette	Fayette County MH/MR Program 100 New Salem Road Suite 118 Uniontown, PA 15401 (412) 430-1370
Forest/Warren	Forest/Warren Department of Human Services 27 Hospital Drive North Warren, PA 16365 (814) 726-2100
Franklin/Fulton	Franklin/Fulton MH/MR Program 425 Franklin Farm Lane Chambersburg, PA 17201 (717) 264-5387
Huntingdon/Mifflin/ Juniata	Juniata Valley Tri-County MH/MR Program 399 Green Avenue Extended, Suite 200 Lewistown, PA 17044-1626 (717) 242-6467
Lackawanna/ Susquehanna/Wayne	Lackawanna/Susquehanna/Wayne MH/MR Program Lackawanna County Building, Room 501 200 Adams Avenue Scranton, PA 18503 (717) 346-5741
Lancaster	Lancaster County MH/MR Program 50 North Duke Street Post Office Box 83480 Lancaster, PA 17608-3480 (717) 295-3680
Lawrence	Lawrence County MH/MR Program 15 West Grant Street New Castle, PA 16101 (412) 658-2538

Lebanon	Lebanon County MH/MR Program 220 East Lehman Street Lebanon, PA 17046 (717) 274-3415
Lehigh	Lehigh County MH/MR/D&A Program 512 Hamilton Street Allentown, PA 18101 (610) 820-6412
Luzerne/Wyoming	Luzerne/Wyoming MH/MR Program 111 North Pennsylvania Boulevard Wilkes-Barre, PA 18701 (717) 825-9441
Lycoming/Clinton	Lycoming/Clinton MH/MR Program Sharwell Building 200 East Street Williamsport, PA 17701 (717) 326-7895 (Main Agency Number)
Mercer	Mercer County MH/MR/CYS Program 8425 Sharon-Mercer Road Mercer, PA 16137 (412) 662-4424
Montgomery	Montgomery County MH/MR/D&A Programs Montgomery County Court House Post Office Box 311 Norristown, PA 19404-0311 (610) 278-3642
Northampton	Northampton County MH/MR Division 520 East Broad Street, Second Floor Bethlehem, PA 18018-6395 (610) 974-7555
Northumberland	Northumberland County MH/MR Program 370 Market Street Sunbury, PA 17801 (717) 988-4434
Philadelphia	Philadelphia County Office of MH/MR 1101 Market Street, 7 th Floor Philadelphia, PA 19107-2907 (215) 685-5460
Potter	Potter County Human Services North Street Post Office Box 241 Roulette, PA 16746 (814) 544-7315 or (800) 800-2560

Schuylkill	Schuylkill County MH/MR Program 420 North Center Street Pottsville, PA 17901-1729 (717) 628-1180
Tioga	Tioga County Human Services Agency Shumway Hill Road Post Office Box 766 Wellsboro, PA 16901 (717) 724-5766
Venango	Venango County MH/MR Administration 1283 Liberty Street Post Office Box 1130 Franklin, PA 16323 (814) 432-9753
Washington/Greene	Washington/Greene County MH/MR Program 504 Courthouse Square Washington, PA 15301 (412) 228-6832
Westmoreland	Westmoreland County MH/MR Program Courthouse Square Extension Greensburg, PA 15601 (412) 830-3617
York/Adams	York/Adams MH/MR Program York County Government Center Third Floor, Suite 301 100 West Market Street York, PA 17401 (717) 771-9618

INFORMATION/HOT LINES

AIDS/HIV	Clinical Trials Information Service	(800) 874-2572
AIDS TREATMENT DATA NETWORK	Provides information on treatments and what drug therapies are and are not covered by public and private insurance.	(800) 743-7104
ARTHRITIS	Arthritis Foundation Information Line	(800) 283-7800
SEXUALLY TRANSMITTED DISEASE HOTLINE		(800) 227-8922
CYSTIC FIBROSIS	Cystic Fibrosis Foundation	(800) 344-4823
DISABILITIES	Health Resource Center In Washington DC	(800) 544-3284 (202) 939-9320
LUNG DISEASE/ALLERGY/ASTHMA	Allergy & Asthma Information Line	(800) 822-2762
LUPUS	Lupus Foundation of America	(800) 558-0121
MULTIPLE SCLEROSIS	Multiple Sclerosis Association of America	(800) 532-7667
MYASTHENIA GRAVIS	Myasthenia Gravis Foundation	(800) 541-5454
NATIONAL CHILD ABUSE HOTLINE		(800) 422-4453
NATIONAL AIDS HOTLINE		(800) 342-AIDS (2437)
NATIONAL AIDS HOTLINE (SPANISH)		(800) 344-SIDA (7432)
NATIONAL COUNCIL OF CHURCHES AIDS TASK FORCE		(212) 870-2298
NATIONAL HOSPICE ORGANIZATION HELPLINE		(800) 658-8898
NORTH AMERICAN NETWORK OF FAMILY SUPPORT PROGRAMS (Families of Pre-term Infants)	Distributed by Shinn & Associates	(517) 332-0211
ORGAN DONATION & TRANSPLANTS	The Living Bank National Marrow Donor Program	(800) 528-2971 (800) 627-7692
PARENT CARE, INC.	Care of High Risk Infants	(800) 543-4932
PEDIATRIC AIDS FOUNDATION		(301) 395-9051
PENNSYLVANIA – THE SPECIAL KIDS NETWORK		(800) 986-4550
PROJECT INFORM	Treatment Information	(800) 822-7422
RARE DISORDERS	National Organization for Rare Disorders	(800) 999-6673

Internet Resources

Site	Address	Comments
AIDS Pathfinder	Http://www.nlm.nih.gov/pnr/etc/aidspath.html	This site will point you to major collections of documents, organizations, and discussion groups on AIDS.
American Diabetes Association	Http://www.diabetes.org	Details on different kinds of insulin.
CancerNet	.gov/hpage/cis.htm	Contains hundreds of handouts on different cancers.
Centers for Disease Control and Prevention	Http://www.cdc.gov	Morbidity and Mortality Weekly Report (MMWR) and Emerging Infectious Diseases. Find extensive guidelines.
Digital Anatomist	.edu/DigitalAnatomist.html	Three-dimensional pictures of various regions of the body. Each picture is linked to a wealth of textual information.
Drug Formulary	.edu/drug.html	Within a few seconds, gives you tables showing, various drugs.
Hospital Web	Http://neuro-www.mgh.harvard	Medical organizations in the U.S. and around the world.
Laboratory Values	Http://www.ghsl.nwu.edu/Norm.html	This online book gives normal lab values for blood, CSF, sweat, and urine.
MedHelp International	http://medhlp.netusa.net/index.htm	Documents on hundreds of conditions and specialized libraries on cancer, brain tumors, drugs and mental health.
Nursing and Health Care Resources	.uk/~exxrw/nurse.html	Newsgroups and mailing lists on nursing, alternative therapy, mental health, midwifery, and related fields.
Nutrition	.edu/tools.htm	The amount of each nutrient contained in the food.
PharminfoNet	http://pharminfo.com	Articles from the <i>Medical Science Bulletin</i> , online.
Psychiatry On-Line	http://www.priory.com/journals/psych.htm	An independent, peer-reviewed electronic journal.
RxList	http://www.rxlist.com/	The most commonly used drugs.
1-800 Numbers for Patient Support Organizations	http://infonet.welch.jhu.edu/advocacy.html	The numbers for patient support groups – related web sites.

Glossary

A

Abduction-Movement of an arm or leg away from the midline of the body.

Adduction-The opposite of abduction, movement of an arm or leg toward the midline of the body.

AFO-Ankle Foot Orthotic – special brace to control or correct deformity.

AIDS-A deficiency of the immune system due to infection with HIV virus.

Apgar Score-A scoring system used to evaluate newborns at 1 minute of life and 5 minutes of life. The total score is effort, muscle tone, reflex irritability, and color. Each of the signs is assigned a score of 0, 1, or 2. The highest possible score is 10.

Apnea Monitor-Medical Device that monitors respirations. Alarm signals if breathing has stopped.

Asphyxia-A condition caused by a decreased amount of oxygen or an excess amount of carbon dioxide in the body.

Asymmetrical Tonic Neck Reflex (ATNR)-A reflex present at birth where turning of the head to one side causes the arm and leg of the face side to straighten, and the opposite arm and leg to bend.

Ataxic CP-Involves using a wide-based gait when standing or walking; may have repetitive movements of extremities.

B

Bilateral -Affecting both sides of the body.

C

Candidiasis-Yeast infection of mouth, esophagus, and lungs.

CDC-Centers for Disease Control – an agency of the Federal Government that provides services for investigation, identification, prevention, and control of disease.

CDC -Child Development Center.

Cerebral Palsy (CP)-A descriptive term applied to a number of nonprogressive motor disorders resulting from gestational or perinatal central nervous system damage and characterized by an impairment of voluntary movement.

Chronic Illness-A disorder or set of symptoms that has persisted for a long time.

Congenital-Born with a person; existing from or from before birth.

Corrected age-Age of the infant minus the weeks born premature.

Crawl-To move with arms, legs and tummy on the floor.

Creep-To move on hands and knees, with tummy off of the floor.

Cryptosporidiosis-Severe and persistent diarrhea caused by a protozoa.

Culture-Represents the vast structure of behaviors, ideas, attitudes, values, habits, beliefs, customs, language, rituals, ceremonies, and practices “Peculiar” to a particular group of people.

Cytomegalovirus-A virus infection occurring at any age and ranging in severity from a silent infection without any consequences through disease manifested by fever, hepatitis, brain damage and death.

D

Diplegia-Refers to double hemiplegia, paralysis of corresponding parts on both sides of body.

Diversity-The fact or quality of being different.

Dyskinetic CP-Characterized by abnormal, involuntary movement, slow work-like movements of extremities, trunk, face or tongue.

E

Early Intervention-Program to determine physical and mental defects in infants and toddlers and to provide short – and long-range treatment.

Extension-The straightening of trunk and limbs. Total extension is the straightening out of all joints of the body. The opposite of flexion.

Extensor thrust-The strong extension of one or more limbs in response to a stimulus.

Extremity-Arms or legs. Upper extremities refers to arms and lower extremities refers to legs.

F

Failure to Thrive-Term used to describe an infant or child whose growth and development pattern falls below the norms for his or her age. Can be organic (physical) cause, or nonorganic (psychological) cause.

Fetal Alcohol Effects-Subtle birth abnormalities (cognitive & behavioral) exhibited in children born to mothers who used alcohol during pregnancy.

Fetal Alcohol Syndrome-Birth defects (physical & behavioral) exhibited in infants born to mothers who chronically abused/used alcohol during pregnancy.

Fine Motor-The area of development concerned with using hands, eyes and eyes and hands together, e.g., reaching, grasping, and coloring. Usually refers to the “finer” or small muscle movements.

Flexion-Decreasing the angle or bending of a joint. The opposite of extension.

G

Gastroesophageal reflux (GER)-A return or backward flow of food.

Gestational Age-The number of complete weeks of fetal development, calculated from the first day of the last normal menstrual period.

Grasp Reflex-Flexion of fingers to tactile stimulation of palm of hand.

Gross Motor-The area of development concerned with how a child controls his larger body movements, e.g., head control, sitting, crawling, walking skills.

H

Hemiplegia-Connotes involvement of both limbs on one side.

Herpes Simplex-Shingles and/or ulcers in anus, mouth, mucous membranes or skin caused by Herpes Simplex Virus.

HIV-Human Immunodeficiency Virus.

Hospice-Physical, psychological, social, and spiritual care for the dying and their families.

Hypertonia-Increase tension of muscles which can make movements more difficult. Sometimes referred as “tight muscles” or “increased muscle tone”.

Hypotonia-The opposite of hypertonia, decreased tension of the muscles, making upright postures difficult to hold. Sometime referred as “floppy” or “decreased muscle tone”.

I

IEP-Individual Education Plan –A document that describes the planning process between school and families.

Individualized Family Service Plan (IFSP)-A document that describes a planning process between families and professionals that results in family identified desired outcomes for an infant-toddler or family.

Interdisciplinary-Care involving all disciplines – family, medical, caseworker, educational, etc.

L

Lymphoid Interstitial Pneumonia-Acute inflammation of lung. Common in children diagnosed with AIDS.

M

MAFO-Molded ankle foot orthotic – special brace to control or correct deformity

Midline-An imaginary line down the center of the body, separating right from left sides.

Mixed Type CP-Involves a combination of spastic and dyskinetic movements.

Morbidity-Incidence of diseased persons or disease in relation to a specific population.

Moro Reflex-Startle movement.

Mortality-Incidence of deaths in relation to a specific population.

N

Neonatal Intensive Care Unit (NICU)-A hospital unit containing a variety of sophisticated mechanical devices and special equipment for the management and care of premature and seriously ill infants.

Nurse-One who is educated in the scientific basis of nursing and is concerned with diagnosis and treatment of human response to actual or potential health problems.

Nutritionist-One who studies diet in the prophylaxis and treatment of disease.

Nystagmus-Rhythmic oscillation of the eyes in a horizontal, vertical, or rotary direction.

O

Occupational Therapist-A licensed professional who treats diseases/disorders by enabling persons to relearn muscular control, coordination, and cope with everyday activity skills.

Orthopedics-The branch of medicine devoted to the study and treatment of skeletal system, joints, muscles and associated structures.

Orthosis-A force system designed to control, correct, or compensate for a bone deformity, deforming forces, or forces absent from the body. Orthosis often involves the use of special braces.

P

Paraplegia-Connotes involvement of both legs, with relative or complete sparing of arms.

Pediatric Neurologist-A physician who specializes in the field of medicine dealing with nervous system and related disorders in children.

Pediatrician-A physician who specializes in children.

Perinatal-The time frame extending from the 28th. Week past conception to the 28th day past birth.

Physical Therapist-A licensed professional who treats disorders or injuries with physical methods such as exercise, massage, heat, electrical current, ultrasound, water, cold.

Pincer Grasp-A mature grasp which involves using only the index finger and thumb only to pick up a tiny object such as a raisin.

Plantar Reflex-The response to stimulation of ball of foot – normally plantar flexion of toes.

Pneumocystitis Carinii Pneumonia (PCP)-A disease of the lung caused by a parasite.

Postnatal-Occurring after birth.

Preeclampsia-Also unknown in the past as toxemia of pregnancy, characterized by high blood pressure, protein in the urine, and edema, or swelling.

Prenatal-Before birth.

Pronation-The hand, wrist, or forearm is rotated so the palm faces downward. The opposite of supination.

Prone-Lying on stomach.

Protective Reactions-Automatic response to prevent falling, e.g., if your child is pushed to the side when he is sitting, he may put his arms out to the side to prevent a fall.

Psychologist-Professional who measures a person's achievement, intelligence, skills, personality, individual and occupational characteristics or potentialities.

Q

Quadriplegia-Connotes involvement of all limbs to a similar degree.

R

Radial-Pertaining to the thumb side of the forearm and hand.

Raking-Picking up small object using the whole hand, fingers against palm, but not the thumb.

Range of Motion-Any body action involving the muscles, joints, and natural directional movement.

Reciprocal-Moving one arm or leg at a time in alternation with the other arm or leg.

S

Shaken Baby Syndrome-Disorders/effects related to abuse from jerking movements inflicted on infant.

Spastic Cerebral Palsy-Characterized by increased muscle tone combined with poor control of posture, balance and decreased coordination.

Spasticity-Hypertonicity or tightness of muscles causing stiff and awkward movements.

Speech Language Pathologist-A licensed professional that helps people with communication problems, speaking, swallowing or other means of communication.

Strabismus-The deviation of one eye from parallelism with the other eye.

Sudden Infant Death Syndrome (SIDS)-Also known as crib death, is defined as the sudden death of an infant under 1 year of age that remains unexplained after a complete postmortem examination, including an investigation of the death scene and a review of the case history.

Supination-Turning of the forearm with palm upward. The opposite of pronation.

Supine-Lying on the back.

Support-To encourage, to enable, to continue, to bear the weight or stress of, to keep from sinking or falling.

Symmetrical movements-Moving corresponding parts of the body simultaneously and in the same direction.

U

Unilateral-Affecting or occurring on only one side of the body.

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