

A  
Writer's  
Reference  
to  
Developmental  
Disabilities



January 1980

Developmental Disabilities Planning Office

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## INTRODUCTION

The Writer's Reference to Developmental Disabilities (DD) is a positively oriented reference book for those who would write about people with developmental disabilities. This Reference is a project of the Public Information Committee of the Governor's Planning Council on Developmental Disabilities. The goal of this book is to educate writers, particularly newspaper and mass media reporters about the field of developmental disabilities.

This Reference was developed to promote a more accurate picture of persons with developmental disabilities, thus preventing some problems that may occur when writing or reporting on this subject. The news media are essential to the public as relayers of information. Only if the media effectively fulfill these roles will the public be informed.

The field of developmental disabilities is a broad one with a unique vocabulary, special programs and activities that are not easy to explain in lay terms. To ensure that the public has adequate information to form correct attitudes, media writers need reliable and accurate information. This reference book on DD is the Governor's Planning Council's effort to help the media inform fairly, accurately, and in the community interest.

A  
Writer's  
Reference  
to  
Developmental  
Disabilities

Governor's Planning Council on  
Developmental Disabilities  
and  
Developmental Disabilities  
Planning Office  
State Planning Agency  
550 Cedar Street  
St. Paul, Minnesota 55101

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Problems that  
Occur in  
Writing about DI

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## Problems — Choosing Words Carefully

One of the first problems that a person faces in researching a story about a person with a developmental disability is the terminology unique to the field. There are common words, yet they may have a very specific meaning when referring to a developmental disability. For instance, “advocate” as defined in the dictionary is different from an advocate for a person with a developmental disability. Also, the technical terms used with developmental disabilities have specific meanings that won’t be found in common dictionaries.

The terminology problem expands when new terms are developed and definitions of old words are updated to provide a more accurate language for people who work in the area of developmental disabilities.

Probably the most confusing aspect of writing about disabilities is the use of euphemisms. Many of these words that started out as a kind way of saying a person had a disability have created imprecise and improper understandings. “Exceptional child,” “developmentally delayed,” and “slow learner” may be well-intentioned ways of referring to a child with mental retardation, but these euphemisms aren’t informative and can create confusion.

At the opposite end of the scale from euphemisms is the present labeling system that sets up expectations and stereotypes, dehumanizes entire groups, and presents a negative image of the developmentally disabled. The use of archaic words from an obsolete classification system, such as “moron,” “idiot,” or “imbecile,” may be used less today, but people persist in using the word “retard” for a person with mental retardation. Another example of careless use is the word “mental” used for both mental illness and mental retardation. Even commonly accepted labels present problems. For example, referring to persons with handicaps as “the handicapped” can be dehumanizing and creates an image of a homogenous and peculiar group.

An additional point to consider when reading or using special DD terminology is the constantly changing “state of the art.” New developments in medicine, psychology, education and legislation give new meanings to words.

## **Problem — Putting People in Pigeon-holes**

It is generally true that people think in stereotypes, that is, equating the labels with the people themselves. It may be convenient to use labels, but labels often confuse and mislead more than they inform. The mass media are full of labels that are shortcuts to saying something about a person, but these labels don't say enough by themselves. Labels we hang on people categorize and dehumanize by select facts we choose to emphasize. Terms like "mental retardation" are very broad; there is probably as much difference within the category as there is between "mental retardation" and "normal."

## **Problems — Confidentiality**

The subject of developmental disabilities also brings up a question of identification and confidentiality. Oftentimes, persons with disabilities and their families are sensitive about their situation. Mistaken facts or identification that appear in a mass medium can be offensive, particularly if a story or picture is not given the proper consideration that special situations demand. As with most stories that appear in the news, subjects should be informed about publication - consent should be obtained where necessary. Special consideration should be given to confidentiality. Identification of juveniles, parents and families may be a touchy area, but if general consideration for the people and the situations is practiced, problems can be avoided.

Acronyms  
and Glossary

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# ACRONYMS

These acronyms and abbreviations are often used with reference to Developmental Disabilities in the state of Minnesota.

<b>AAMD</b>	<i>American Association on Mental Deficiency</i>
<b>ACLD</b>	<i>Association for Children with Learning Disabilities</i>
<b>ARC</b>	<i>Association for Retarded Citizens</i>
<b>ARRM</b>	<i>Association of Residences for Retarded in Minnesota</i>
<b>BEH</b>	<i>Bureau of Education for the Handicapped</i>
<b>CAIR</b>	<i>Community Alternatives and Institutional Reform</i>
<b>CCS</b>	<i>Crippled Children's Services (now SCH)</i>
<b>CEP</b>	<i>Comprehensive Epilepsy Program</i>
<b>CEC</b>	<i>Council for Exceptional Children</i>
<b>CETA</b>	<i>Comprehensive Employment and Training Act</i>
<b>CHPA</b>	<i>Comprehensive Health Planning Agency</i>
<b>CP</b>	<i>Cerebral Palsy</i>
<b>CWD</b>	<i>County Welfare Department</i>
<b>DAC</b>	<i>Developmental Achievement Center</i>
<b>DES</b>	<i>Department of Economic Security</i>
<b>DD</b>	<i>Developmental Disability</i>
<b>DDU</b>	<i>Disability Determination Unit (Social Security)</i>
<b>DPW</b>	<i>Department of Public Welfare</i>
<b>DVR</b>	<i>Division of Vocational Rehabilitation (Department of Economic Security)</i>
<b>ECSU</b>	<i>Educational Cooperative Service Unit</i>
<b>EFA</b>	<i>Epilepsy Foundation of America</i>
<b>EPS</b>	<i>Early and Periodic Screening</i>
<b>EL</b>	<i>Epilepsy League</i>
<b>EMR</b>	<i>Educable Mentally Retarded</i>
<b>FG</b>	<i>Foster Grandparents</i>
<b>GED</b>	<i>General Educational Development</i>
<b>HEW</b>	<i>Health, Education, Welfare (now HHS)</i>
<b>HHS</b>	<i>Health and Human Services (formerly HEW)</i>
<b>HIDD</b>	<i>Hearing Impaired Developmentally Disabled</i>
<b>HSA</b>	<i>Health Services Agency (formerly CHPA)</i>

ICF	<i>Intermediate Care Facility</i>
MAMH	<i>Minnesota Association for Mental Health</i>
MARC	<i>Minneapolis Association for Retarded Citizens</i>
MCH	<i>Minnesota Council for the Handicapped</i>
MDH	<i>Minnesota Department of Health</i>
MEL	<i>Minnesota Epilepsy League</i>
MHB	<i>Metropolitan Health Board</i>
MHMRI	<i>Mental Health-Mental Retardation Inebriety</i>
MinnARC	<i>Minnesota Association for Retarded Citizens</i>
MinnDACA	<i>Minnesota Developmental Achievement Center Association</i>
MISCCA	<i>Minnesota Society for Crippled Children and Adults (Courage Center)</i>
MRA	<i>Minnesota Rehabilitation Association</i>
MR	<i>Mental Retardation</i>
NSAC	<i>National Society for Autistic Children</i>
OHI	<i>Office for Handicapped Individuals</i>
PACER	<i>Parent Advocacy Coalition for Educational Rights</i>
PCEH	<i>President's Committee on Employment of the Handicapped</i>
PCMR	<i>President's Committee on Mental Retardation</i>
P.L.	<i>Public Law</i>
RDC	<i>Regional Development Commission</i>
SCH	<i>Services for Children with Handicaps (formerly CCS)</i>
SLD	<i>Special Learning Disability</i>
SERC	<i>Special Education Regional Consultant</i>
SLF	<i>Supervised Living Facility</i>
SPA	<i>State Planning Agency</i>
SPARC	<i>St. Paul Association for Retarded Citizens</i>
SRS	<i>Social and Rehabilitation Services</i>
SSDI	<i>Social Security Disability Income</i>
SSI	<i>Supplemental Security Income</i>
TMR	<i>Trainable Mentally Retarded</i>
UJCP	<i>United Cerebral Palsy</i>
UJHF	<i>United Handicapped Federation</i>
WAC	<i>Work Activity Center</i>
YARC	<i>Youth Association for Retarded Citizens</i>

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# Glossary

**Accessibility** Generally, buildings and structures modified to enable persons with limited mobility to move in or about these buildings and structures. Accessibility is a requirement under all federally funded projects.

**Adaptive Behavior** The effectiveness with which an individual meets the standards of personal independence and social responsibility expected of his age and cultural group. Three aspects of this behavior are maturation, learning, and social adjustment.

**Advocacy** Under the D.D. Act, advocacy is a system, independent of service providers, to protect D.D. persons by use of legal, administrative and other remedies. Advocacy can also be one person intervening on the behalf of another, with permission, when the other person is unable to successfully act in his own behalf.

**Ambulatory** Able to walk or move about independently.

**Anticonvulsant** A chemical agent that arrests or prevents convulsions or seizures.

**Aphasia** Partial or total loss of the ability to articulate ideas in any form, resulting from brain damage.

**Assessment** Individual evaluation of a person's performance or development which can be used in educational and/or program planning and which may result in special education instruction and services.

**Ataxic** Pertaining to loss or lack of muscular coordination.

**Athetoid** A condition in which there is a constant, slow, involuntary movement, usually an extending and flexing of the fingers and hands.

**Autism** A severe disturbance of mental and emotional development that appears in childhood. Symptoms include absent or limited speech, monotonously repetitive body movements, social withdrawal and involvement with inanimate objects rather than people. Autism is not to be confused with mental retardation.

**Barrier Free** Building, facility, or area that is completely accessible to persons having mobility problems.

**Behavior Disabilities** Socio-emotional disorders manifesting behavioral dysfunction including problems of mental illness, mental retardation, chemical dependency, and related problems.

**Behavior Modification** The control of learning environment through a planned systematic application of the principles of learning in shaping an individual's behavior to minimize or eliminate negative behavior and to emphasize and reinforce positive behavior.

**Case Management** The coordination of a person's involvement with various agencies/services (making sure a person doesn't get lost in the system).

**Cerebral Palsy** A group of medical conditions characterized by nerve and muscle dysfunctions.

**Competency Test** An evaluation of an individual to determine whether he is legally capable of making choices and legally responsible for his actions; applies to a person with mental illness or mental retardation as well as a minor.

**Conservatorship** A limited form of supervision tailored to meet the needs and abilities of a person with a disability. Conservatorship is like guardianship, but persons under a conservatorship retain certain rights.

**Coordination** The joining of elements of social-services so that compatibility and cooperation among elements are maximized.

**Counseling** Professional guidance on the basis of knowledge of human behavior and the use of special interviewing skills to achieve specified goals which are beneficial to the individual and mutually accepted by counselor and client.

**Crippled** Now archaic, it referred to a person who was partially disabled or deficient in a specific way.

**Deaf** Severely or profoundly unable to hear and understand at the ordinary conversation level with or without hearing aids. There is no such thing as a typical deaf person. The term "the deaf" should not be used to connote a homogenous faceless group.

**Developmental Disability** A severe, chronic disability of a person which

- is attributable to a mental or physical impairment or combination of mental and physical impairments;
- is manifested before the person attains age twenty-two;
- is likely to continue indefinitely;
- results in substantial functional limitations in three or more of the following areas of major life activity: self-care, receptive and expressive language, learning, mobility, self-direction, capacity for independent living, and economic self-sufficiency; and
- reflects the person's need for a combination and sequence of special, interdisciplinary, or generic care, treatment, or other services which are of lifelong or extended duration and are individually planned and coordinated.

**Developmental Period** Up to age 22 (see definition of "Developmental Disability.")

**Deinstitutionalization** The acts of preventing new admissions to institutions, returning residents of institutions to appropriate residential programs in the community, creating an environment at institutions which fosters resident development and insures protection of clients' rights.

**Down's Syndrome** A type of mental retardation associated with specific physical characteristics due to a chromosomal abnormality.

**Diagnosis** The process of determining the nature and origin of a disabling condition by examination of the symptoms.

**Dysfunction** Disordered or impaired function of a bodily system or organ.

**Dyslexia** Impairment of the ability to read; a disability characterized by reading, spelling, and various language disabilities observed in children with normal intelligence who are otherwise, at least, average in academic and social achievement.

**Educable** Individuals, usually classified as having mental retardation, who exhibit characteristics that indicate the capability of becoming socially adjusted and economically independent at a minimum level, or persons with mildly retarded mental and adaptive behavior who demonstrate ability to be semi-independent and can learn academic skills near the 6th grade level.

**Epilepsy** A disorder of the central nervous system marked by sudden and periodic lapses of consciousness, and distinctive, usually measurable disturbances in the electrical discharges within the brain.

**Evaluation** An appraisal or estimation of certain specific characteristics, such as intelligence, personality, physical aspects, or vocational readiness of an individual.

**Exceptional** In education, a word used to describe a child whose abilities or intelligence are exceptionally high or low.

**Family Foster Care** Care provided by foster parents usually with the supervision and financial support of a child placement agency.

**Guardianship** A legal status providing protection, care, and management of a person considered incapable of managing his own affairs.

**Governor's Planning Council on Developmental Disabilities** Described in detail elsewhere in the Guide.

**Group Home** A licensed home with designated substitute parents. Persons who have retardation placed in group and family care homes may participate in special education, vocational or day care facilities in the community.

**Hard of Hearing** Residual hearing loss which still allows hearing, understanding and connected speech to some degree.

**Handicap** Condition, especially anatomical, physiological, or mental, that prevents or restricts normal achievement. *Multiple Handicap* having more than one handicap. *Substantial Handicap* physical or mental disability of such severity that, alone or in connection with social, legal, or economic constraints, it requires the provision of special services over an extended period of time.

**Hearing Impairment** Refers to the entire range of auditory impairment from deaf to hard of hearing.

**Hyperactivity** Excessively or abnormally active.

**Impaired** Diminished strength, ability or use.

**Independent Living Skills** Appropriate behavior necessary for living in a non-institutionalized setting. Skills include transportation, maintenance of clothes and living quarters, personal hygiene, money handling, group living, and recreation.

**Institutionalization** The inhibiting and dehumanizing effects on a person's development that results when he is placed in an institution where there is limited sensory stimulation and limited personal experiences.

**Institutional Reform** Movement to change institutions so as to eliminate the negative effects mentioned above or modification or improvement of the total institutional environment to ensure maximum individual development in the least restrictive environment possible.

**Intermediate Care Facility (ICF)** Facility for persons with mental retardation or related conditions; a facility primarily for the diagnosis, treatment, or rehabilitation of persons who are mentally retarded or have related conditions.

**I.Q.** Intelligence Quotient, a numerical rating determined through psychological testing which indicates approximately the relationship of a person's mental age (MA) to his chronological age (CA).

**Learning Disability** Any defect in a person's ability to learn one of the basic academic disciplines, or general defect in learning to write, or in learning mathematics in which the cause is not easily determined.

**Legally Blind** Less than a corrected vision of 20/200 in the better eye or visual field contraction of 20 degrees or less.

**Mainstreaming** The effort to include and keep disabled individuals in the regular school system class structure.

**Mental Age** A measure of mental development, determined by intelligence tests expressed as the age at which that level is average.

**Mental Deficiency** (see Mental Retardation)

**Mental Retardation** A characteristic which develops early in life and is manifested by a below average rate of learning and social adjustment. There is a wide range within which the learning and social adjustment rates occur.

**Mongolism and Mongoloid** Archaic term for Down's Syndrome.

**Nervous System** The coordinating mechanism that regulates internal body functions and responses to external stimuli; includes brain, spinal cord, ganglia, and nerves.

**Neurological Condition** A disorder of the nervous system.

**Nonambulatory** Not able to walk.

**Non-mobile** Not moving or incapable of moving, not able to be moved from place to place.

**Ombudsman** Person who conducts an impartial investigation into an issue or case and assumes an advocate role if the results of the investigation warrant it.

**Organic** Ordinarily used in reference to the causative role of certain anatomical or physiological changes, diseases, or trauma in existing mental or emotional disorders.

**Perceptual Problems** Difficulties in perceiving things, being aware of things, or using the senses, particularly sight and hearing.

**Prevention and Early Intervention** System of programs to educate in the prevention of developmental disabilities through early care.

**Protective Services** A system of social, legal, or other appropriate services which assists individuals unable to manage their own resources or to protect themselves from neglect, exploitation, or hazardous situations without assistance from others.

**Psychotic** Relating to a mental disorder causing distortion or disorganization of a person's mental capacity.

**Rehabilitation** To restore to useful life through education or therapy.

**Residential Facility** A facility or residential program which provides housing and appropriate supervision for individuals requiring developmental or behavioral assistance on a 24-hour basis outside the individual's home.

**Respite Care** Short term, temporary care of a person with a developmental disability so the person's family can take a vacation or handle a family crisis.

**School Age** a) the ages 7-16 during which children are required by the state's compulsory attendance law to attend school; b) the ages 5-18 when most students attend school; c) for the handicapped students, school age means the ages 4-21 when public schools are required to provide special education services.

**Screening** Refers to a method of identifying possible handicapped students by giving a series of health or educational tests to a large group of children.

**Seizure** A lapse or impairment of consciousness originating in the brain. A seizure may be accompanied by abnormal motor and sensory functions.

**Sheltered Employment** A structured program providing partial self-support through the employment of the handicapped worker under conditions which allow a reduced production rate, special work supervision, limited job duties, or special job engineering, training, and adaptive equipment.

**Sheltered Workshop** A facility that provides individuals who are not able to work in competitive employment with an opportunity to train and work in a controlled environment at their level of functioning.

**Slow Learner** A child with social and academic behavior less than usual age level standards.

**Spastic** Refers to a type of cerebral palsy.

**Special Education** Educational services provided for exceptional children who deviate physically, mentally, or socially from the regular class so that the standard curriculum is not suitable for their educational needs.

**State Planning Agency** Described in detail elsewhere in Guide.

**Trainable** A person with moderate or severe retardation who has very limited potential for independent living and who achieves a minimum of academic skills.

**Treatment** Provision of specific physical, social, or mental interventions which halt, control, or reverse processes which cause, aggravate, or complicate malfunctions or dysfunctions.



# Resources

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## **Sources of Information - Agencies**

It is often necessary to contact some authority to verify a fact, explain something, or obtain some first-hand information. A listing of agencies and organizations follows. These organizations can provide needed information or refer you to someone who can.

### **STATEWIDE**

#### **DIVISION OF VOCATIONAL REHABILITATION**

Department of Economic Security  
3rd floor Space Center Building  
444 Lafayette Road  
St. Paul, Minnesota 55101  
Telephone 612/296-5616

#### **FOSTER GRANDPARENTS**

Minnesota Association for Retarded Citizens  
3225 Lyndale Avenue South  
Minneapolis, Minnesota 55408

#### **GOVERNOR'S PLANNING COUNCIL ON DEVELOPMENTAL DISABILITIES**

Developmental Disabilities Planning Office  
State Planning Agency  
200 Capitol Square Building  
550 Cedar Street  
St. Paul, Minnesota 55101  
Telephone 612/296-4018

#### **HANDICAPPED HOUSING SERVICE, INC.**

Metro Square Building  
7th & South Robert Streets  
St. Paul, Minnesota 55101  
Telephone 612/222-1813

#### **LEGAL ADVOCACY FOR THE DEVELOPMENTALLY DISABLED OF MINNESOTA**

222 Grain Exchange Building  
323 Fourth Avenue South  
Minneapolis, Minnesota 55415  
Telephone 612/338-0968

#### **MINNESOTA ASSOCIATION FOR CHILDREN WITH LEARNING DISABILITIES**

1821 University Avenue  
St. Paul, Minnesota 55104  
Telephone 612/646-6136

**MINNESOTA ASSOCIATION OF DEAF CITIZENS**

8355 Glenbrook Avenue South  
Cottage Grove, Minnesota 55016

**STATE DEPARTMENT OF EDUCATION**

Special Education Division  
8th Floor Capitol Square Building  
550 Cedar Street  
St. Paul, Minnesota 55101  
Telephone 612/296-4163

**STATE DEPARTMENT OF PUBLIC WELFARE**

MR Division  
Centennial Office Building  
St. Paul, Minnesota 55155  
Telephone 612/296-2158  
Deaf Services Division  
296-8978 (voice)  
296-4850 (tty)

**MINNESOTA ASSOCIATION FOR RETARDED CITIZENS**

3225 Lyndale Avenue  
Minneapolis, Minnesota 55408  
Telephone 612/827-5641

**MINNESOTA EPILEPSY LEAGUE**

Citizen's Aid Building  
404 South Eighth Street, Room 242  
Minneapolis, Minnesota 55404  
Telephone 612/340-7630

**MINNESOTA DEVELOPMENTAL ACHIEVEMENT CENTER  
ASSOCIATION**

Room South 280, Griggs Midway Building  
1821 University Avenue  
St. Paul, Minnesota 55105  
Telephone 612/647-9200

**MINNESOTA DEPARTMENT OF HUMAN RIGHTS**

240 Bremer Arcade Building  
St. Paul, Minnesota 55102  
Telephone 612/222-6226

**MINNESOTA STATE COUNCIL FOR THE HANDICAPPED**

208 Metro Square Building  
7th and South Robert Streets  
St. Paul, Minnesota 55101  
Telephone 612/296-6785

**MINNESOTA STATE SERVICES FOR THE BLIND**

1745 University Avenue  
St. Paul, Minnesota 55104  
Telephone 612/296-6080

**PARENT ADVOCACY COALITION FOR EDUCATIONAL RIGHTS CENTER, INC.**

4701 Chicago Avenue  
Minneapolis, Minnesota 55407  
Telephone 612/827-2966

**UNITED CEREBRAL PALSY OF MINNESOTA, INC.**

Griggs-Midway Building  
1821 University Avenue  
St. Paul, Minnesota 55104  
Telephone 612/646-7588

**YOUTH MinnARC**

same as Minnesota Association for Retarded Citizens.

**NATIONAL PROGRAMS**

**AMERICAN ASSOCIATION ON MENTAL DEFICIENCY**

5201 Connecticut Avenue NW  
Washington, D.C. 20015  
Telephone 202/686-5400

**BUREAU OF EDUCATION FOR THE HANDICAPPED**

U.S. Office of Education  
ROB No. 3, Room 2100  
7th and D Streets SW  
Washington, D.C. 20202  
Telephone 202/245-9661

**COUNCIL FOR EXCEPTIONAL CHILDREN**

1920 Association Drive  
Reston, Virginia 22091  
Telephone 703/620-3660

**DEVELOPMENTAL DISABILITIES BUREAU**

Office of Human Development  
Department of Health and Human Services  
330 C Street SW  
Washington, D.C. 20201  
Telephone 202/245-0870

**EPILEPSY FOUNDATION OF AMERICA**

1828 L Street NW  
Washington, D.C. 20036  
Telephone 202/293-2930

**FEDERATION OF THE HANDICAPPED, INC.**

211 West 14th Street  
New York, New York 10011  
Telephone 212/242-9050

**HOUSING COMMITTEE FOR THE  
PHYSICALLY HANDICAPPED, INC.**

c/o Department of Social Services  
Room 6111 Harlem Hospital Center  
506 Lenox Avenue  
New York, New York 10037

**INTERNATIONAL ASSOCIATION OF REHABILITATION  
FACILITIES**

No. 955, 5530 Wisconsin Avenue  
Washington, D.C. 20015  
Telephone 202/654-5882

**NATIONAL ASSOCIATION FOR RETARDED CITIZENS**

P.O. Box 6109  
2709 Avenue E East  
Arlington, Texas 76011  
Telephone 817/261-4961

**NATIONAL ASSOCIATION OF COORDINATORS OF STATE  
PROGRAMS FOR THE MENTALLY RETARDED**

Suite 802, 2001 Jefferson Davis Highway  
Arlington, Virginia 22202  
Telephone 703/920-0700

**NATIONAL ASSOCIATION OF THE DEAF**

814 Thayer Avenue  
Silver Spring, Maryland 20910  
Telephone 301/587-1788, 587-1789

**NATIONAL CONFERENCE ON DEVELOPMENTAL DISABILITIES**

c/o Developmental Disabilities Planning Office  
200 Capitol Square Building  
550 Cedar Street  
St. Paul, Minnesota 55101  
Telephone 612/296-4018

**NATIONAL REHABILITATION ASSOCIATION**

1522 K Street NW  
Washington, D.C. 20005  
Telephone 202/659-2430

**NATIONAL SOCIETY FOR AUTISTIC CHILDREN**

Suite 1017  
1234 Massachusetts Ave, NW  
Washington, D.C. 20005  
Telephone 202/783-0125

**PARENT'S CAMPAIGN FOR HANDICAPPED CHILDREN  
AND YOUTH**

1201 16th Street NW  
Suite 607E  
Washington, D.C. 20036  
Telephone 202/833-4160

**PRESIDENT'S COMMITTEE ON MENTAL RETARDATION**

7th and D Streets SW  
Washington, D.C. 20201  
Telephone 202/245-7634

**PRESIDENT'S COMMITTEE ON EMPLOYMENT  
OF THE HANDICAPPED**

Washington, D.C. 20210  
Telephone 202/961-3401

**REHABILITATION SERVICES ADMINISTRATION**

Room 3006, Switzer Building  
330 C Street SW  
Washington, D.C. 20201  
Telephone 202/245-8492

**UNITED CEREBRAL PALSY ASSOCIATION, INC.**

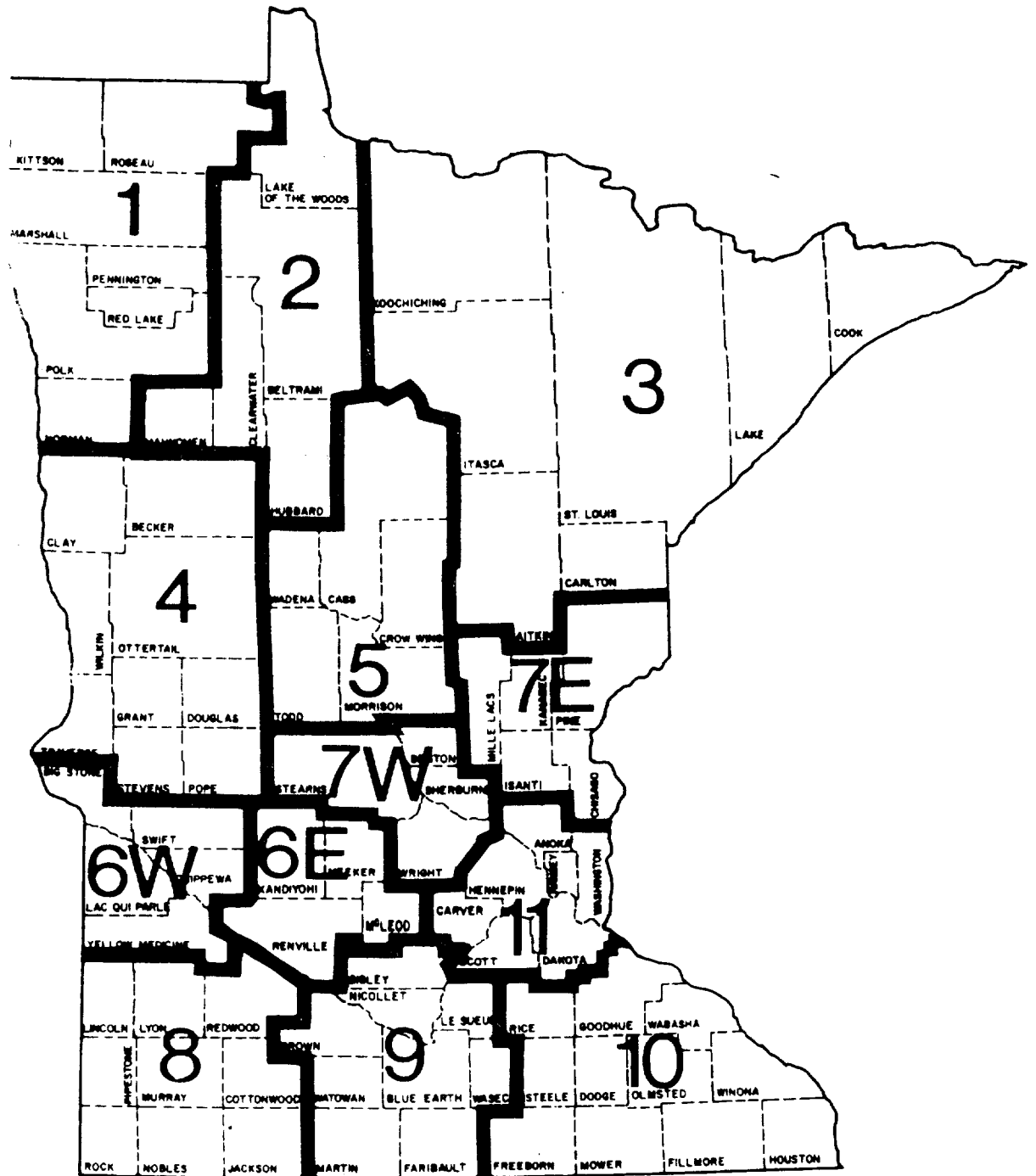
3rd Floor, 66 East 34th Street  
New York, New York 10016  
Telephone 212/889-6655

**LOCAL PROGRAMS**

Many state and national programs and agencies have local offices. These local offices may be able to provide more specific or regional information. Information about contacting local offices can be obtained through Developmental Disabilities Regional Planning Offices listed on the following pages. Organizations with local offices include:

Association for Retarded Citizens  
County Welfare Department  
Developmental Achievement Centers  
Epilepsy League (Minnesota)  
Foster Grandparent Program  
Minnesota Literacy Council  
Mental Health and Hearing Impaired Program  
St. Paul-Ramsey Medical Center  
Senior Companion Program  
United Cerebral Palsy

# Developmental Disabilities Regional Planning Offices



- Region 1** Developmental Disabilities Advisory Board  
N.W. Regional Development Commission  
425 Woodland Avenue  
Crookston, Minnesota 56716  
Telephone 218/281-1396
- Region 4** Developmental Disabilities Planning Council  
West Central Regional Development Commission  
Fergus Falls Community College  
Fergus Falls, Minnesota 56537  
Telephone 218/739-3356
- Region 6E** Developmental Disabilities Advisory Board  
Regional Development Commission  
(Upper Minnesota Valley RDC, Southwest RDC)  
City Auditorium  
311 West 6th Street  
Willmar, Minnesota 56201  
Telephone 612/235-8504
- Region 6W** Developmental Disabilities Advisory Committee  
6 East Regional Development Commission  
(Upper Minnesota Valley RDC, Southwest RDC)  
same address and telephone as Region 6E as above
- Region 7E** Developmental Disabilities Advisory Council  
East Central Regional Development Commission  
Kanabec County Courthouse  
18 North Vine Street  
Mora, Minnesota 55051  
Telephone 612/679-4065
- Region 8** Developmental Disabilities Advisory Committee  
6 East Regional Development Commission  
(Upper Minnesota Valley RDC, Southwest RDC)  
same address and telephone number as Region 6E above
- Region 9** Developmental Disabilities Planning Council  
Region 9 Development Commission  
P.O. Box 3367 120 South Broad Street  
Mankato, Minnesota 56001  
Telephone 507/387-5643
- Region 10** Developmental Disabilities Planning Council  
Southeast Minnesota Regional Development Commission  
301 Marquette Bank Building  
2nd Street SE and South Broadway  
Rochester, Minnesota 55901  
Telephone 507/285-2583



**Region 11**    Developmental Disabilities Task Force  
Metropolitan Health Board  
Metropolitan Council  
300 Metro Square Building  
7th and Robert Streets  
St. Paul, Minnesota 55101  
Telephone 612/291-6364

## Sources of Information - Bibliographies\*

The following pages contain a list of bibliographies, periodicals, and other sources that may provide background information, insight or stories.

### *Aids to Advocacy for Developmentally Disabled Persons*, January 1979.

A selected bibliography and resource guide covering several aspects of developmental disabilities with special attention to advocacy. Prepared by and available through:

Developmental Disabilities Protection and Advocacy System  
Developmental Disabilities Planning Office  
State Planning Agency  
200 Capitol Square Building  
550 Cedar Street  
St. Paul, Minnesota 55101  
Telephone 612/296-4018

### *Bibliography Series*

NARC Library, P.O. Box 6109, 2709 Avenue E East, Arlington, Texas 76011.

### *Citizen Advocacy Bibliography*

Six-page bibliography covering books, periodicals and audio-visual materials on citizen advocacy. Available: Assn. for Retarded Citizens, 2709 Avenue E. East, Arlington, Texas 76011

### *"Reintegrating Mentally Retarded People Into the Community."* Council for Exceptional Children.

(Program for the Analysis of Deinstitutionalization Resource Council for Exceptional Children, 1920 Association Drive, Reston, Virginia 22091.)

An annotated bibliography of print and audiovisual information and training materials.

### *Legal Rights and the Mentally Retarded Offender*

First in series of nine bibliographies compiled by National Assn. of Retarded Citizens Library. Includes sections on Basic Civil Rights, Right to Education, Right to Treatment, Guardianship, and the Mentally Retarded Offender.

Available: NARC Library  
P.O. Box 6109  
2709 Avenue E East  
Arlington, Texas 76011

\*Taken directly from *Aids to Advocacy - A Bibliography and Resource Guide*, DD Protection and Advocacy System, DD Planning, Minnesota State Planning Agency, January 1979.

*Mental Disability Law Report*

A publication of the American Bar Association on the Mentally Disabled, 1800 M Street, N.W., Washington, D.C. 20036. Issue 1 (1) contains a retrospective legal and technical bibliography intended for use by attorneys.

*Number IV, Marriage, Parenthood, and Family Life for the Mentally Retarded.*

One of nine bibliographies. Available: National Assn. for Retarded Citizens Library, P.O. Box 6109, 2709 Avenue E. East, Arlington, Texas 76011.

*Advocacy: Resources and Approaches.* Paul, J.L., Rosenthal, S., & Adams, J.

Washington, D.C., Office of Human Development (HHS), 1976.

*Region V: Selected Publications*

Listing of books, articles, conference proceedings, media products, selected by Region V Consortium Project or the Regional Development Disabilities Information Center for the period 1976 to the present.

Available: Region V Consortium Project

Ohio State University

Nisonger Center

Columbus, Ohio

or

Regional Developmental Disabilities

Information Center

317 Knutson Drive

Madison, Wisconsin 53704

*The Exceptional Child and the Law* Smith, Frank Tupper, Jr. and Smith, Jill.

Contains four major areas: legal factors and/or problems relevant to the exceptional individual within the family setting, society at large, the educational setting, and the medical or psychological service setting.

Available: United Cerebral Palsy Assn., Inc.

66 East 34th Street

New York, New York 10016

(212) 889-6655

*Reintegrating Mentally Retarded People Into the Community*

Programs for the Analysis of Deinstitutionalization Resources. An annotated bibliography of print and audiovisual information and training materials.

Available: Council for Exceptional Children

1920 Association Drive

Reston, Virginia 22091

*Resource Guide to Literature on Barrier-Free Environments.1977*

Available: Architectural and Transportation Barriers Compliance Board

Room 1010 Switzer Bldg.  
330 C Street, S.W.  
Washington, D.C. 20201

**Training Institute for Human Service Planning, Leadership and Change Agency.** Syracuse University, 805 South Crouse Avenue, Syracuse NY 13210.

The institute is willing to share unpublished reading lists used by participants in the TI program. Some lists are annotated.

# INFORMATION RESOURCES

## **National Association for Retarded Citizens, Citizen Advocacy Division**

2709 Avenue E East  
P.O. Box 6109  
Arlington, Texas 76011  
(812/261-4961)

See also: NARC Publications List: Booklets/pamphlets on education, general handicap, architectural planning, recreation, religion, research, and residential services.

*Directory of National Information Sources on Handicapping Conditions and Related Services* 405 p.

Office for Handicapped Individuals Clearinghouse  
Superintendent of Documents  
U.S. Government Printing Office  
Washington, D.C. 20403  
Order No. 017-000-00196-5     \$6.00 per copy.

*Enablers: (Information Clearinghouse, Program Review, Management Training for Metropolitan Youth Serving Organizations)*, 104 West Franklin Avenue, Minneapolis, Minn. 55404.

*Mainstream on Call* (national toll free wats line) Provides answers to questions arising out of complex federal regulations, particularly those related to Sections 503 and 504 of the Rehabilitation Act of 1974. Free service available Monday through Friday, 8 a.m. to 4 p.m. Central Standard Time, by calling (800)/424-8089. Hot Line provided by Mainstream, Inc., non-profit organization promoting the mainstreaming of disabled persons in employment and education. Provides accurate, updated information about laws affecting the handicapped and answers questions on compliance. Serves corporations, educators and service providers, as well as disabled individuals concerned about their rights. Confidentiality is maintained at all times, although complex questions in specific cases are referred to experts in federal enforcement and implementation agencies.

*Minnesota Guidebook to State Agencies, 1978-79.*     500 p.

Available: Office of the State Register  
Suite 415, Hamm Building  
St. Paul, Minnesota 55102  
\$5.15 per copy. (tax included)

Lists almost 100 state agencies and over 1,000 state offices. Contains map, telephone directory, and offers 50 pages of subject matter index for easy reference to services and programs.

**Mental Health Law Project**

1751 N. Street, N.W.  
Washington, D.C. 20036

MHLP is engaged in an effort to define and implement the rights of the mentally ill and mentally retarded through a program of litigation, education of the bar and the public, and related activities.

**National Center for a Barrier-Free Environment**

840 Connecticut Avenue  
Washington, D.C. 20015

**National Center for Law and the Deaf**

7th and Florida Avenue N.E.  
Gallaudet College  
Washington, D.C. 20002  
Telephone 202/447-0445

**National Center for Voluntary Action (NCVA)**

1214 16th Avenue, N.W.  
Washington, D.C. 20036  
Telephone 202/467-5560

National Center affiliated with network of over 300 Voluntary Action Centers.

**National Information and Referral Service for Autistic and Autistic-Like Persons**

No 06 31st Street  
Huntington, West Virginia 25702  
Telephone 304/697-2638

Organization objective: Maximize effectiveness of volunteer programs through assistance to program leadership. (Library of 12,000 documents)

**Project Share**

Reference Division  
P.O. Box 2309  
Rockville, Maryland 20852  
Telephone 301/881-4063

An information clearinghouse created by the Department of Health and Human Services to provide information which can help improve the management of human services. Will collect and disseminate project descriptions, descriptions of innovative practices, evaluation and survey reports, thesis and research reports, published and unpublished papers.

**Special Education Section**

Minnesota Department of Education  
550 Cedar Street  
St. Paul, Minnesota 55101

**State-Federal Information Clearinghouse for Exceptional Children**

The Council for Exceptional Children

1411 South Jefferson Davis Highway

Jefferson Plaza Suite 900

Arlington, Virginia 22202

Computer-based information system for retrieval of information  
pertaining to government and the education of handicapped  
children.

## **MINNESOTA NEWSLETTERS**

*ACLD Newsletter*

Minnesota Association for Children with Learning Disabilities

494 North

1821 University Avenue

St. Paul, MN 55104

*Advocacy Dimensions*

Developmental Disabilities Planning Office

550 Cedar Street, Room 200

St. Paul, MN 55101

*ARRM Newsletter*

Association of Residences for the Retarded in Minnesota

459 Rice Street

St. Paul, MN 55103

*Charles Thompson, Hall Newsletter*

(deaf citizens)

1824 Marshall Avenue

St. Paul, MN 55104

Telephone 612/644-3455

*D.D. News Briefs and Calendar*

Developmental Disabilities Planning Office

550 Cedar Street, Room 200

St. Paul, MN 55101

*D.D. News Letter*

Developmental Disabilities Planning Office

550 Cedar Street, Room 200

St. Paul, MN 55101

*ECHOES*  
Southeastern Minnesota Chapter  
NSAC  
2920 5th Avenue NW  
Rochester, MN 55901

*EPI-SOTA*  
Minnesota Epilepsy League  
404 South 8th Street  
Suite 242  
Minneapolis, MN 55404

*FOCUS*  
Minnesota Association for Retarded Citizens  
3225 Lyndale Avenue  
Minneapolis, MN 55408

*G.O.V.S. Newsletter*  
Governor's Office of Volunteer Services  
130 State Capitol  
St. Paul, MN 55155

*HANDI-CAPTIONS*  
Minnesota State Council for Handicapped  
208 Metro Square Building  
7th and Robert  
St. Paul, MN 55101

*Information Exchange*  
Metro D.D. Task Force/Health Board  
300 Metro Square Building  
7th and Robert Streets  
St. Paul, MN 55101

*JOURNAL*  
Minnesota Developmental Achievement Center Association  
433 East Little Canada Road  
St. Paul, MN 55117

*MARC Times*  
Minneapolis Association for Retarded Children  
2344 Nicollet Avenue South  
Minneapolis, MN 55404

*MARF Newsletter*  
Minnesota Association of Rehabilitation Facilities  
550 South Snelling Avenue  
St. Paul, MN 55116



*MCEC Newsletter*  
Minnesota Council for Exceptional Children  
Box 294  
Fergus Falls, MN 56537

*MSSA Information Bulletin*  
Minnesota Social Service Association  
614 Portland Avenue  
St. Paul, MN 55102

*NEWSLETTER*  
Minnesota West Metro Chapter  
NSAC  
3725 47th Avenue South  
Minneapolis, MN 55406

*Newsletter*  
Minnesota Association for the Education of Young Children  
1821 University Avenue, Room 378 S.  
St. Paul, MN 55104

*NEWSLETTER*  
Spina Bifida Association of Minnesota  
1639 E. Nevada Avenue  
St. Paul, MN 55106

*MAVD Newsletter*  
Minnesota Association of Volunteer Directors  
319 15th Avenue S.E.  
Minneapolis, MN 55455

*Newsletter*  
Society for Autistic Children  
530 2nd Avenue N.W.  
New Brighton, MN 55112

*PACE SETTER*  
Parent Advocacy Coalition for Educational Rights  
4701 Chicago Avenue  
Minneapolis, MN 55407

*Parenttalk*  
St. Paul Association for Retarded Citizens  
529 Jackson Street, Room 329  
St. Paul, MN 55101

*Public Health Pulse*  
Minnesota Department of Health  
717 Delaware Street, S.E.  
Minneapolis, MN 55440

*SPEAK OUT/STEPPING OUT NEWS*  
Suburban Community Services  
6800 Cedar Lake Road  
Minneapolis, MN 55426

*THE LINK*  
Enablers Inc./Youth Services  
104 West Franklin  
Minneapolis, MN 55404

*The Progress*  
United Handicapped Federation  
1951 University Avenue  
St. Paul, MN 55104

## NATIONAL NEWSLETTERS/JOURNALS

*ADVOCATE*  
NSAC  
1234 Massachusetts Avenue NW  
Washington, D.C. 20005

*Advocate Exchange: A Forum for Citizen Advocacy Coordinators*  
Quarterly newsletter of the Citizen Advocacy Functional Division of NARC. It is a forum for citizen advocacy coordinators. It contains a calendar of events, descriptions of reference materials and pertinent articles.  
Available: Assn. for Retarded Citizens  
2709 Avenue E East  
Arlington, Texas 76011  
Cost: Free to division members

*Advocacy for Children*  
Quarterly newsletter.  
Available: HHS  
Office of Child Development  
Box 1182  
Washington, D.C. 20013  
Cost: No Charge

*AMICUS*  
Magazine on Advocacy, published six times per year.  
Available: National Center for Law and the Handicapped, Inc.  
1235 North Eddy Street  
South Bend, Indiana 46617  
Cost: \$10.00 per year

*ARISE* (American Research Institute in Special Education)

Magazine concerning the handicapped. Published 10 times yearly.  
Available: American Research Institute in Special Education  
376 Bay 44th Street  
Brooklyn, New York 11214

*ARRM Newsletter*

Published monthly.  
Available: Association of Residences for the Retarded  
459 Rice Street  
St. Paul, MN 55103

*Clearinghouse Review*

This is perhaps the most comprehensive publication on the legal rights of the disabled and disadvantaged. It is available at most law school libraries.

Available: National Clearinghouse for Legal Services  
500 North Michigan Avenue  
Suite 1940  
Chicago, Illinois 60610

*Common Sense from Closer Look*

Newsletter of the Parents Campaign for Handicapped Children and Youth.

Available: Parents Campaign for Handicapped Children and Youth  
Box 1492, Washington, D.C. 20013

*Consumer Advocacy*

Newsletter written for and by consumer members of Developmental Disabilities Councils and other interested consumer groups.

Available: Consumer Advocacy  
Developmental Training Center  
Indiana University  
2853 East Tenth Street  
Bloomington, Indiana 47401

*Insight*

Published monthly by the Council for Exceptional Children, 1920 Association Drive, Reston, Virginia 22091

Monthly periodical giving indepth attention to all facets of governmental decisions regarding special individuals. Deals with litigation, legislation, publications, research projects, funding trends, etc.

*In the Mainstream*

Bi-monthly newsletter published by Mainstream, non-profit organization promoting the mainstreaming of disabled persons in employment and education. Free upon request. For subscription write: Mainstream, Inc., 1200 15th Street, N.W., Washington, D.C. 20005.

Affirmative action newsletter printing articles from governmental agencies enforcing regulations on compliance, updates on state and federal legislation, and reports on other developments in the field.

*Mental Disability Law Reporter*

Published by the American Bar Association Commission on the Mentally Disabled, 1800 M Street, N.W., Washington, D.C. 20036. Reporting on the legal developments taking place daily affecting persons with a mental disability and discussions on the implications of those developments.

*Mental Retardation and the Law (magazine)*

Available: HHS Office of Mental Retardation Coordination  
Washington, D.C. 20402  
Cost: No Charge

*Polling Magazine*

United Cerebral Palsy of New York City, Inc., 122 East 23rd Street,  
New York, N.Y. 10010.

*The Advocate for Human Services*

A monthly Washington roundup of legislation and activities affecting social work and people. Published by the National Association of Social Workers, 1425 H. Street, N.W., Suite 600, Washington, D.C. 20003.

*UAP Reporter*

Newsletter of the American Association of University Affiliated Programs for the Developmentally Disabled, 2033 M. Street, N.W., Suite 406, Washington, D.C. 20036.

*Word from Washington*

Monthly newsletter, reviewing issues of interest in the developmental disabilities field. Publication of United Cerebral Palsy Assns., Inc., Epilepsy Foundation of America, and National Society for Autistic Children.

Available: United Cerebral Palsy Association  
Suite 141  
Chester Arthur Building  
425 I. Street Northwest  
Washington, D.C. 20001

# **Organizational Arrangement of Developmental Disabilities Council and Offices**

Federal law requires that in each state, two organizations work jointly and with other agencies and groups to plan and improve coordination of services for people with developmental disabilities – a Governor's Planning Council on Developmental Disabilities (DD Council) and a state administrative organization. In Minnesota, the designated state agency is the Developmental Disabilities Office of the State Planning Agency.

The State DD Council and the DD Planning Office are responsible for planning and evaluating comprehensive services for people with developmental disabilities in Minnesota. While they do not provide direct services to persons with developmental disabilities, they work with other agencies and organizations, public and private, that do provide services, to promote expansion, development, coordination, and improvement of existing services.

The SPA awards grants for projects which explore, plan, coordinate, or provide new services to people with developmental disabilities. Upon recommendation of the State DD Council, they attempt to develop an intergovernmental planning framework which links federal, state, and local government together with consumers and providers of services in a coordinated statewide effort.

Appointed by the Governor, the Council members represent principal state and local agencies and nongovernmental organizations concerned with services for people with developmental disabilities. At least one-half of the members are developmentally disabled or represent someone who is developmentally disabled. The Council meets on the first Wednesday of each month; its meetings are open to all interested persons.

Staff members of the DD Planning Office work with the Council in planning and administering a variety of activities. The Office is part of the Minnesota State Planning Agency.

Activities of the Council and Office include planning, evaluation, public information, legislative and plan review, research and development, systems advocacy activities, education and training, and promoting and supporting development of appropriate services for persons with developmental disabilities.

At the local level, regional DD planning programs and their advisory Councils work in conjunction with the State Council to plan and stimulate coordinated services for developmentally disabled persons in each geographical area. These regional planning offices are set up on a contractual basis between the State Planning Agency and the local Regional Development Commission.

Organization of  
State Agency

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