A Writer's Reference to Developmental Disabilities



January 1980

Developmental Disabilities Planning Office

TABLE OF CONTENTS

	Page
Introduction	iv
Problems that Occur in Writing about DD	1
Acronyms	5
Glossary	9
Resources	15
Agencies	17
Bibliographies	25
Information Resources	28
Periodicals	30
Organization of State Agency	37

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 ulfill these roles will the public be informed.

The field of developmental disabilities is a broad one with a unique rocabulary, special programs and activities that are not easy to explain in ay 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 nelp the media inform fairly, accurately, and in the community interest.

Problems that
Occur in
Writing about DI

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 meduim 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

ACRONYMS

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

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

[CF Intermediate Care Facility MAMH Minnesota Association for Mental Health Minneapolis Association for Retarded Citizens MARC Minnesota Council for the Handicapped **MCH** Minnesota Department of Health MDH MEL Minnesota Epilepsy League MHB Metropolitan Health Board Mental Health-Mental Retardation Inebriety MHMRI MinnARC Minnesota Association for Retarded Citizens MinnDACA Minnesota Developmental Achievement Center Association MISCCA Minnesota Society for Crippled Children and Adults (Courage Center) MRA Minnesota Rehabilitation Association MR Mental Retardation **NSAC** National Society for Autistic Children THC Office for Handicapped Individuals Parent Advocacy Coalition for Educational Rights PACER CEH President's Committee on Employment of the Handicapped President's Committee on Mental Retardation ²CMR > I ... Public Law 3DC Regional Development Commission **SCH** Services for Children with Handicaps (formerly CCS) H.D. Special Learning Disability Special Education Regional Consultant SERC SLF Supervised Living Facility SPA State Planning Agency St. Paul Association for Retarded Citizens SPARC SRS Social and Rehabilitation Services SDI Social Security Disability Income SSI Supplemental Security Income Trainable Mentally Retarded **IMR** JCP United Cerebral Palsy JHF United Handicapped Federation VAC Work Activity Center

Youth Association for Retarded Citizens

CARC

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 connotate 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

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.

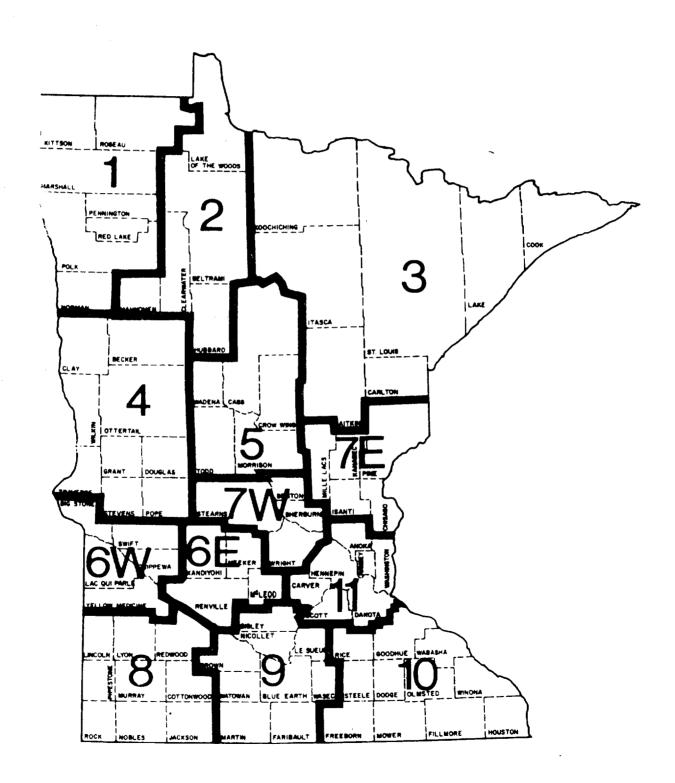
3rd Floor, 66 East 34th Street New York, New York 10016 Telephone 212/889-6655

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 Progam
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, an other sources that may provide background information, insight or storideas.

Aids to Advocacy for Developmentally Disabled Persons, January 1979.

A selected bibliography and resource guide covering several aspect 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-visumaterials on citizen advocacy. Available: Assn. for Retarde 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, Restor 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 complied by National Assn. C Retarded Citizens Library. Includes sections on Basic Civil Right-Right to Education, Right to Treatment, Guradianship, and th 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 Resourc Guide, DD Protection and Advocacy System, DD Planning, Minnesot 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

01

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 Agentry. 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 watts 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

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