

INFORMATION EXCHANGE



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METROPOLITAN COUNCIL DD PROGRAM NEWS 1988 AGENDA: REALIZING THE VISION

A new year, a new agenda. Last year's theme, quality and integration, provided a series devoted to explaining new terms and ideas, as well as current activities and suggestions to better understand and utilize the thematic concepts. 1987 brought the publication of the booklet and videotape, "A New Way of Thinking" produced by the Minnesota Governor's Planning Council on Developmental Disabilities. These two items clearly explained and dramatically portrayed the new vision many have for people with developmental disabilities to live lives of quality as integrated members of their communities. 1987 also brought a strategy that would go far to actualize that vision when the Medicaid amendments (S 1673 and H 3454), known as the Home and Community Quality Services Act, were introduced in the U.S. Congress.

1988's agenda, "Realizing the Vision," will be devoted to how to make the vision become reality. As in last year's series, key terms and ideas will be explained and very practical suggestions will be offered to assist readers to move from the vision to actions that plan, design, deliver and evaluate services in an integrated community. (See article on PCMR Conference in this issue).

Home and community-based services are so limited by eligibility criteria and availability (even for those eligible) that traditional services must begin to offer more opportunities for genuine integration. Here is one checklist to apply to organizations that provide services to persons with developmental disabilities. The "no" answers will provide you with indicators of where you should seek improvements. This kind of action is a step toward "realizing the vision".

TEST YOUR IQ . . . INTEGRATION QUOTIENT FOR ORGANIZATIONS SERVING PEOPLE WITH DEVELOPMENTAL DISABILITIES* (Answer "yes" or "no")

ADMINISTRATION

1. Does your organization have a written policy, position, or mission statement affirming the value of community integration for the individuals it serves?

2. Has your organization provided in-service training on integration values, principles, and practices in the past year to:

- a. Administrative staff? _____
- b. Supervisory and direct care staff? _____
- c. Board of directors? _____
- d. Clients' families? _____
- e. Organization volunteers? _____

3. Does your organization provide all staff and families up-to-date information on integration resources such as notices of relevant conferences, workshops, presentations by leading-edge professionals or recent books, journal articles, studies, and reports that feature integration concepts, principles and practices, and other state-of-the-art materials? _____

Continued on next page . . .

EMPLOYMENT OPPORTUNITY - DEVELOPMENTAL DISABILITIES METROPOLITAN COUNCIL

This is a senior planner level position responsible for administering the Council's regional D.D. policy plan. Work involves maintenance of the current plan; analysis and recommendation of appropriate revisions; provision of technical assistance to agencies, consumers and service providers; coordination of completing service initiatives; publication of monthly newsletter; support to advisory committee; review of services, legislation and regulations for consistency with Council policies; securing and administering DD project grants. Qualified applicants must have a thorough and demonstrable knowledge of policy planning, the target population and service system in the developmental disabilities area; proven skill in grant writing and administration; good written and oral communication skills; and ability to work independently. Starting salary \$32,552. Excellent benefits. Call Employee Relations at 291-6368 for application. Applications will be accepted until 5:00 p.m. Jan. 15.

METROPOLITAN COUNCIL
300 Metro Square Building
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WE ARE AN EQUAL OPPORTUNITY EMPLOYER

Activities, notices, services, products, etc. mentioned in this publication are for information purposes only and do not imply endorsement by the Developmental Disabilities Programs of the Metropolitan Council and the State Planning Agency.

4. Does your organization provide space on the premises (e.g., a library, resource room, bulletin board, or shelves) to display or circulate notices, articles, or books, on integration? _____

5. Does your organization provide tangible incentives (time off, registration fees, promotions, wage increases) to encourage professional development to keep current with new ideas in the field? _____

CLIENTS

6. Do each of the clients you serve have an Individual Plan (Service, Program, Habilitation, Education, or Written Rehabilitation) that addresses basic human needs:

- a. To improve personal status, the plan should include activities designed to enhance self-image, abundant opportunities to make choices, and skills to reduce dependence on others for self-care? _____
- b. To increase community stature, the plan should include activities that are generally valued by members of society who are not disabled. Typical community activities include getting a library card and using it, shopping as individuals rather than in groups, going to regular education classes with other children or adults who are not disabled? _____

7. Do each of your clients have at least four socially valued roles such as:

- a. Homeowner, tenant, or housemate (not facility resident)? _____
- b. Community volunteer or member of local club or group for people who are not disabled? _____
- c. Participant or spectator in community sports, a library card owner? _____
- d. A student in the local school or in regular adult education or vocational training classes, an employee in a business with a majority of coworkers who are not disabled, a friend or companion of at least two people who are not disabled other than family and staff? _____

ENVIRONMENT

8. Do the environments in which your clients spend most of their time reflect:

- a. Attitudes that affirm they have potential to grow that has yet to be developed regardless of their past performance? _____
- b. Expectations that are high, demand higher achievements than past experience would predict, and recognize that the limitations of their environments may have held them back more than their disabilities? _____
- c. Age-appropriate settings, training materials, and equipment? _____
- d. Community-referenced skill and behavior training? _____
- e. Functional tasks and activities that are expected and valued by the community for persons their age? _____
- f. Individualized approaches that are in a natural

proportion (ratio of persons with disabilities to those who are not disabled) in living, learning, working, and social arrangements? _____

*Developed for the Minnesota Governor's Planning Council on Developmental Disabilities.

LIBRARY ADDITIONS

The following publications are now available on loan for Metropolitan Area residents only. Please call 291-6364 to make sure someone is available to sign-out materials. Readers in Greater Minnesota may use library resources provided by the State DD Program Office. Call (612) 291-4018 or TDD 296-9962. See last page of this newsletter.

American Association of University Affiliated Programs for Persons with Development Disabilities; **Developmental Handicaps: Prevention and Treatment IV.**

Maryland State Planning Council on Developmental Disabilities; **You Can Do It!**

PCMR CONFERENCE ON INTEGRATION

The President's Committee on Mental Retardation (PCMR) will convene a national conference on February 3-5, 1988 in Washington, D.C. The conference will be "A Presidential Forum: Citizens with Mental Retardation and Community Integration." It has been planned in order to examine what is happening and what needs to happen to achieve genuine community integration of people with mental retardation.

The conference will open with presentations on the current partnerships among various entities in the service field (e.g., federal/state, state/local, public/private, family/provider). The heart of the conference will be the panels that will focus on living arrangements, employment, transportation, education, recreation/leisure/socialization, family supports/respite care, life services planning/quality assurance, health care and citizen advocacy.

Panelists will include leading professionals, people with mental retardation and parents from around the country. Colleen Weick, Director, Governor's Planning Council on Developmental Disabilities, is the only panelist from Minnesota.

Participants will hear each panel address the same three questions:

- What does it take to plan, design, deliver and evaluate (panel topic, e.g., education) in order to promote maximum community integration?
- What can PCMR do to influence federal policy makers and legislators on issues and legislation relating to community integration of citizens who are mental' regarded?
- What are the federal/state, state/local, public/private and family/provider implications for this (panel topic, e.g., living arrangements)?

The conference will produce recommendations to the Secretary of Health and Human Services, a report to the President, a videotape summary of the proceedings, and a technical assistance manual for use by all sectors to design, deliver and evaluate exemplary program models that promote genuine community integration.

Over twenty federal, state and local organizations and agencies are co-sponsoring this conference including the Minnesota University Affiliated Program/Center for Residential and Community Services. For registration information: Rosa Singletary or Nancy Borders; PCMR; U.S. Department of Health and Human Services; Office of Human Development Services; Washington, D.C. 20201; (202) 245-9563.

CONSUMER CASE MANAGEMENT PROJECT

The Association for Retarded Citizens Suburban is offering a new project to train and support adults with developmental disabilities, parents and guardians to be active participants in case-management decisions regarding assessment for needed services and designing service plans. Volunteers will act as mentors for the person with developmental disabilities. The project is funded by a combination of grants from the Governor's Planning Council on Developmental Disabilities, the McKnight Foundation, the Huestad Foundation and its affiliate, Drovers First American Bank. People interested in being a volunteer mentor should call Marijo McBride, (612) 431-3700.

RIGHTS STATEMENT

A recent issue of "**Independently Speaking**," newsletter of the Metropolitan Center for Independent Living provided this information:

Persons who are in need of, and receive, home care (personal care assistant) services are in vulnerable positions. They have a right to quality and respectful care regardless of whom they select to provide those services. To assure that adequate protections are in place, the 1987 Minnesota Legislature adopted the following Bill of Rights for persons who are recipients of home care (personal care assistant) services:

Statement of Rights for Recipients of Personal Care Services

A person who receives home care services has these rights:

- 1) the right to receive written information about rights, including what to do if rights are violated;
- 2) the right to receive care and services according to a suitable and up-to-date plan, and subject to accepted medical or nursing standards, to take an active part in creating and changing the plan and evaluating care and services;
- 3) the right to be told about the services that are being provided or suggested, about other choices that are available, and about the consequences of these choices including the consequences of refusing these

services;

- 4) the right to refuse services or treatment;
- 5) the right to know, in advance, any limits to the services available from a provider, whether the services are covered by health insurance, medical assistance, or other health programs, and the provider's ground for a termination of services;
- 6) the right to know what the charges are for services, no matter who will be paying the bill;
- 7) the right to know that there may be other services available in the community, including other home care services and providers, and to know where to go for information about these services;
- 8) the right to choose freely among available providers and to change providers after services have begun, within the limits of health insurance, medical assistance, or other health programs;
- 9) the right to have personal, financial, and medical information kept private;
- 10) the right to be allowed access to records and written information from records;
- 11) the right to be served by people who are properly trained and competent to perform their duties;
- 12) the right to be treated with courtesy and respect;
- 13) the right to be free from physical and verbal abuse;
- 14) the right to reasonable notice of changes in services or charges;
- 15) the right to a coordinated transfer when there will be a change in the provider of services;
- 16) the right to know how to contact an individual associated with the provider who is responsible for handling problems and the name and address of the state or county agency to contact for additional information or assistance; and
- 17) the right to assert these rights without retaliation.

NEW PARKING LAW

The 1987 Legislature amended parking laws for persons with handicaps. Several changes were enacted:

Parking Certificates: Application/Eligibility--

- New parking certificates must be obtained by all eligible people by December 31, 1988. New certificates will cost \$5.
- Applications must include a physician's statement certifying a disability and whether it is temporary or permanent.
- Persons with disabilities of long duration or considered permanent will be issued certificates valid for up to six years. Renewed certificates will cost \$5.
- Certificates will be designed so temporary or permanent types are easily distinguishable.

Parking License Plates: Application/Eligibility--

- Same as for parking certificates. Plates will have international symbol for handicap. Cost is same as regular license plate fees with a \$1 credit for each month registered.
- Parking privileges include parking in a space designated "handicapped parking space" or at a meter without paying meter. Parking is NOT allowed in "time-limited", "no-parking", or "specially reserved"

parking zones.

Parking Violations:

- \$500 fine for physicians fraudulently certifying a disability for eligibility purposes.
- \$500 fine for property owners who fail to keep "handicapped parking spaces" free of obstructions.
- \$500 fine for fraudulent use of plates/certificates.
- \$100 - \$200 fine for unauthorized parking in designated parking spaces.

For more information on the new law and any new developments: Minnesota Council on Disability; (612) 296-6785 or 1-800-652-9747, V/TDD.

TWIN CITIES MAGAZINE FEATURE

Twin Cities Magazine's December, 1987 issue, includes a sensitively-written article about the Association for Retarded Citizens Minnesota. Sally Swallen, former DD Advisory Committee member, is one of two parents featured in the story. If you wish to obtain a copy, send a check for \$2.50 to Dorn Communications; 7831 East Bush Lake Road; Minneapolis, MN 55435-3875. The publisher will donate \$1 to the ARC Minnesota for each order received. Readers may wish to send comments about the article to the editor, Marcia Appel, at Dorn Communications. These responses could encourage more accurate and sensitive portrayals of people with developmental disabilities in the media.

FOR YOUR INFORMATION

Seeking Authors

Very Special Arts - Minnesota (VSA-MN) invites contributions of poetry or essays on the topic of disability for publication in "**Promising Practices**". Send a typed or printed copy of your work together with your name and address to: VSA-MN; Poetry; 5701 Normandale Road, Suite 315; Edina, MN 55424.

Supported Employment Issues Paper

The Minnesota Council on Disability has published a new issue paper, "**Supported Employment--Commonly Asked Questions and Answers**." To receive a free copy, send a stamped, self-addressed envelope to the Minnesota Council on Disability; 208 Metro Square Bldg.; St. Paul, MN 55101.

U.S. Constitution in Braille

A free copy of the U.S. Constitution in Braille may be obtained by sending a request to: The National Braille Press; 88 Stephens Street; Boston, MA 02115 or call (617) 266-6160. This offer is made possible by a grant from the National Endowment for the Humanities.

RESOURCES AND SERVICES

Technology Hot-Line

Readers who want information about, or help with technological advances may call the IBM National Support Center for Persons with Disabilities. The Center also wants to hear about the needs of people with disabilities who use their products. The hot-line number is 1-800-IBM-2133 or (404) 988-2729 (TTY).

"Birding" Booklet

The National Library Service for the Blind and Physically Handicapped of The Library of Congress, Washington, DC 20542, has published the first in a projected series of leisure activities booklets, "**Birding: An Introduction to Ornithological Delights for Blind and Physically Handicapped Individuals**." The booklet discusses "the possibilities of birding" as a hobby for people who have sight or physical handicaps. "Sound is as important as sight in identifying bird species," says NLS director Frank Kurt Cylke. "In fact, many people find the calls more reliable."

The introduction to birding states, "You will be introduced to a midwestern group of visually impaired birders; the importance and variety of bird sounds; a selection of recorded and braille books available through your regional and subregional library; sources of commercial recordings of bird songs; and a club where you can associate with individuals holding a mutual interest in birding." The "**Birding**" handbook is available upon request from the Reference Section, National Library Service for the Blind and Physically Handicapped, Library of Congress, Washington, DC 20542.

REQUESTS FOR ASSISTANCE

Melpomene Institute, the Active Woman's Health Resource, a non-profit organization, is seeking study participants for an innovative study to look at the following: factors that affect physical activity routines, the role of physical activity in physical and mental health of women with disabilities, and the relationship between disability and body image. Participants are asked to fill out a six page questionnaire concerning their lifestyle, physical activity, and personal concerns. Responses to the questionnaire, which are confidential and will remain anonymous, are needed from women with disabilities at all levels of fitness. Melpomene Institute will inform research participants of this study's results. Participants in other Melpomene Institute studies report great satisfaction in increasing their knowledge and personal insight. For more information or to participate, send a stamped self-addressed envelope to: Melpomene Institute; 2125 E. Hennepin Ave.; Minneapolis, MN 55413 or call (612) 378-0545.

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HERBERT LOVETT HIGHLIGHTS SUCCESSFUL BEHAVIORAL PRINCIPLES BASED ON INDIVIDUAL RESPECT AND DIGNITY

On October 7, 1987, Herbert Lovett visited Minnesota to address the Governor's Planning Council on Developmental Disabilities and guests. Lovett, a clinical psychologist from Boston, Massachusetts, serves as a consultant to many residential, vocational, and training programs throughout the United States and Canada. He is also the author of a recent book entitled **Cognitive Counseling and Persons with Special Needs: Adapting Behavioral Approaches to the Social Context** which is available from the lending library of the Governor's Planning Council on Developmental Disabilities.

Central to Lovett's thoughts and experiences is that far too often behavioral principles, sound enough in themselves, are applied without considering individual needs and choices. Such approaches either fail to change the behavior or they draw counselor and the person with a disability into deeper conflict. He maintains that behavior analysts have misused behavior management by trying to **control** behavior rather than to use it as it was intended--as a teaching device. Trying to change a person's behavior through escalating control is condescending. One teaches most effectively when the individual is respected. What is powerful is a relationship where positive learning is rewarded.

Lovett described the typical cycle of increasing control over a person with a disability. Through exhibited behavior, the individual is communicating, "I want." The behavior is labeled as attention seeking, noncompliant, or avoidance. The staff or family member typically reacts by means of control such as ignoring, redirecting, or differential reinforcement procedures. The individual exhibits more behaviors because the person believes that he/she has not been heard in the first place. The staff or parents then increase the contingencies and use time out, physical restraint, mechanical restraint, and chemical restraint. The individual still does not desist, "I will not give up." The behavioral control increases to pain and systematic abuse. The individual may give up and the staff/parents proclaim success in control.

Lovett pointed out that in some states and provinces there are ladders of increasingly aversive procedures that end in using cattle prods hundreds of times a day. Such efforts to "control" puts people at risk. People have died because of the use of such aversive treatment.

"We need to look at the environmental context to

assess whether there is dignity," he said. "Instead of talking about optimum size of residential facilities, we need to know each person individually and ask each person where he or she wants to live. Choice means being responsive to needs, feelings, and real world responsibilities. Understanding comes only through the establishment of a positive, caring relationship with another person. Put respect, positive regard, and common sense back into relationships," Lovett implored.

We need to move from external control approaches to internal control, Lovett suggested. Don't use a "no" without providing choices and the opportunity to demonstrate competence. For example, rather than saying, "No--don't do that!" try, "Here, you can do this or this." By such responses, you are demonstrating and anticipating respect. Remember that in everyday relationships, we give attention to people because they call out or ask when they need our support. Friendship means that you matter, someone needs you, and that you need others. The people with whom we work need to know that they are needed and that someone cares. More often than not, they never get to know this. Some pointers are: talk less, listen more, admit mistakes, help the person to name what they need, remember that change is mutual in a real relationship, and never walk away from anyone who is in need. Above all, the value placed on a person is the foundation of successful therapy.

A videotaped (VHS) interview with Herbert Lovett, conducted by Larry Ringer of the Legal Advocacy Services for Persons with Developmental Disabilities, is available on a loan basis from: Governor's Planning Council on Developmental Disabilities; 300 Centennial Office Building; 658 Cedar Street; St. Paul, MN 55155. Tel. (612) 296-4018, or (612) 296-9962 (TDD or voice).

PARENTS ARE EQUAL PARTNERS

What rights do parents have, especially with regard to their children who have disabilities? According to Charlotte Des Jardins, Director of the Coordinating Council for Handicapped Children (Chicago), in her book, **How to Get Services by Being Assertive**, parents need to know their rights as well as be more assertive if they are to be effective advocates on behalf of their child with a handicap. Her handbook is dedicated to the premise that parents are equal partners with professionals in the development of their child's full potential, that they are the **authority** on their own child, and that they have the following rights:

1. the right to claim their just share in partnership with

their professional helpers and in planning their child's future;

2. the right to be informed of their rights;
3. the right to question decisions made concerning their child, especially when they do not agree with these decisions;
4. the right to all the services for their child who has a handicap that the law grants them;
5. the right to an appropriate education for their child at public expense;
6. the right to inspect and challenge the contents of their child's school records;
7. the right to challenge any professional decision with which they do not agree;
8. the right to a due process hearing when they do not agree with school placement decisions;
9. the right to ask that their child receive all the benefits and privileges granted to average children;
10. the right to make mistakes without feeling guilty.

"Parents often express feelings of ignorance, intimidation, guilt, defensiveness, frustration, anger, bewilderment, helplessness, and feelings of being patronized, condescended to, and overwhelmed, in their meetings with professionals," writes the author. "These feelings are all feelings of nonassertion," she concluded. To purchase this publication and others on similar topics, contact: Coordinating Council for Handicapped Children; 220 South State Street, Room 412; Chicago, IL 60604. Tel. (312) 939-3513.

EARLY CHILDHOOD REGIONAL COORDINATOR PROJECT LAUNCHED

The Minnesota Department of Education has announced the establishment of regional coordination and technical assistance on early childhood services through each of the ten regional Education Cooperative Service Unit (ECSU) offices. This three-year project is jointly funded through Part H of Public Law 99-457 and Early Childhood Grant Discretionary monies. It is designed to assist parents, local Interagency Early Intervention Committees, school districts, local and regional health and human service agencies, and other providers to cooperatively plan and implement services for young children from birth through age five who are handicapped or at risk of becoming handicapped and their families. For more information about the project and a listing of those serving as regional coordinators, contact: Jan Rubenstein, Minnesota Department of Education; Capitol Square Building, Eighth Floor; 550 Cedar Street; St. Paul, MN 55101. Tel. (612) 296-7032.

MINNESOTA TECHNICAL ASSISTANCE RESOURCE NETWORK ON SUPPORTED EMPLOYMENT ESTABLISHED

The Minnesota Supported Employment Project, through a collaborative effort with the Minnesota University Affiliated Program on Developmental Disabilities at the University of Minnesota, has announced the establishment of a statewide technical assistance effort to help those who are providing or are planning to

offer supported employment services. Called the Minnesota Technical Assistance Resource Network, this project will provide information, materials, and expertise to human service agencies participating in supported employment programs. Mr. Ron Erickson will be serving as coordinator of the project and will have primary responsibility for the day-to-day operation of the Network. David R. Johnson will be serving as Project Director. For more information, call: (612) 296-5629, or (800) 328-9095 toll free.

PUBLIC AFFAIRS COMMITTEE NEEDS VOLUNTEERS

The Epilepsy Foundation of Minnesota is seeking people to serve on a Public Affairs Committee. Each year this committee reviews pending legislation at the state and national levels. Issues are selected prior to the upcoming legislative session such as access to employment, health, or auto insurance. Become involved by contacting Anne Barnwell, Advocacy Services Coordinator; Epilepsy Foundation of Minnesota; 672 Transfer Road; St. Paul, MN 55114. Tel. (612) 646-8675, or (800) 292-7932, toll free.

A STORY THAT I HEARD

The following selection is from **A Story That I Heard: A Compendium of Stories, Essays, and Poetry about People with Disabilities and American Life**, collected by David B. Schwartz, John McKnight, and Michael Kendrick, published by the Pennsylvania Developmental Disabilities Council, 1987:

The Open Door Club

Tryna Hope

One day, Ruthann arrived at the meeting with a news article that disturbed the members of the club. Six men with mental retardation, all known to the people in the group, were facing discrimination while trying to rent a two-flat apartment house on Olive Street in Northampton. This was not the first time that the rights of individual group members had been challenged concerning housing.

The meeting was filled with energy, anger, and pain. But it was also filled with ideas. It was decided to hold a speak-out, a media event, a two-hour amount of time in which people with mental retardation would speak about their lives in institutions and their lives in the community.

The speak-out was held in the Superior Courtroom in Northampton. Two hundred and fifty people attended. Radio, television, and newspaper reporters had set up their equipment and were interviewing people as they arrived. Open Door members and other speakers were practicing their comments in the judge's chambers.

I made the opening statements. I spoke about communication and challenged the audience to listen to people speak in a way they had never listened before. I charged them with the responsibility of maintaining an

openness to people with real concerns who may look, speak, or act differently. Then I introduced the first speaker.

Michael came to the microphone with a friend. He spoke eloquently for about a minute, gesturing and making eye contact with the audience. He was compelling the quiet, attentive audience to understand him. However, because of a speech disability, few, if any, people understood him. When Michael finished speaking, he turned to his friend who smiled and said:

"Michael just said that he is excited to be here talking to you tonight. He said that when he lived in the institution, everything was white. But now, he has color all around him. His room is blue, his bed is brown, his sheets have flowers on them, and the house he lives in is red. He said color is important to all people, but especially to him who lived without it for so long. He said he is a good neighbor and is glad to live in the community."

There was a long pause . . . and suddenly the room was filled with standing, clapping, crying people.

Tryna Hope is a social worker who is an advisor to the Open Door Club in Northampton, Massachusetts.

PUBLICATIONS

Living with Lowe's Syndrome: A Guide for Families, Friends, and Professionals, Lowe's Syndrome Association, 1987. This booklet is about a relatively rare disease named after Dr. Charles Lowe, who along with Drs. Terrey and MacLachlan first recognized it as a syndrome in 1952. Also known as the oculo-cerebro-renal syndrome, reflecting the three major organ systems involved in the disorder (eye, brain, and kidney), Lowe's Syndrome is a hereditary condition that affects only males. It is believed to be caused by a single defective gene on the X-chromosome. The Lowe's Syndrome Association was formed in 1983 to promote better understanding of the syndrome. They publish a newsletter three times per year. Membership is \$15.00. The Second International Conference on Lowe's Syndrome will be held on June 17-19, 1988, at the Oak Brook Hills Hotel in Chicago. For a copy of the booklet and other information, contact: Lowe's Syndrome Association, Inc.; 222 Lincoln Street; West Lafayette, Indiana 47906. Tel. (317) 743-3634.

MINNESOTA UNIVERSITY AFFILIATED PROGRAM ON DEVELOPMENTAL DISABILITIES, University of Minnesota, 1987. This is a new brochure which describes the Minnesota University Affiliated Program on Developmental Disabilities, developed to promote interdisciplinary training, service, technical assistance, research, and dissemination activities which are designed to enhance community services and social support for individuals with developmental disabilities. For copies of the brochure and other information, contact: MUAP; 6 Pattee Hall; 150 Pillsbury Drive, Southeast; Minneapolis, MN 55455. Tel. (612) 624-4848.

Transition for Persons with Deaf-Blindness and Other Profound Handicaps: State of the Art, Angela M. Covert and H.D. Bud Fredricks (Eds.), Teaching Research Publications, 1987. This is a compilation of the proceedings and presentations from a national conference on transition services for youth with profound/multiple handicaps such as deaf-blindness. Primary emphasis is on community living options, supported competitive employment, health and psychosocial issues, and recreation and leisure options. To order, send check for \$10.00, with your name, address, phone numbers (business and home) to: Teaching Research Publications; 345 North Monmouth Avenue; Monmouth, OR 97361.

CONFERENCES/WORKSHOPS

January 21 and 22, 1988

Channeling the Energy is the theme of the 1988 Minnesota Association of Rehabilitation Facilities Annual Training Conference that will be held at the Radisson Minnetonka Hotel. For more information, contact: MARF; S-376 Griggs Midway Building; 1821 University Avenue; St. Paul, MN 55104. Tel. (612) 646-0900.

February 28 through March 4, 1988

Learning about Normalization through PASS 3 is a intensive workshop that will be held at the Doublewood Inn, Fargo, North Dakota. Program Analysis of Service Systems (PASS) is a tool for assessing the quality of human service programs, and is an effective means of learning more about the principle of normalization. The workshop will be led by John O'Brien and Connie Lyle from Atlanta, Georgia. For more information, contact: Jane Wells; Creative Community Options; 4209 Oakmede Lane; White Bear Lake, MN 55110. Tel. (612) 426-9263.

FUTURE EVENTS

March 18-22, 1988

The American Society on Aging will hold its 34th Annual Meeting in San Diego, California, at the Town & Country Hotel. Surgeon General C. Everett Koop has been invited to address the opening general session on the conference theme, *An Aging Society Is Everyone's Business*. A special feature will be a Technology Education Center making available hands-on demonstrations. For additional information and registration, contact: American Society on Aging; 833 Market Street, Suite 512; San Francisco, CA 94103. Tel. (415) 543-2617.

August 14-18, 1988

The First International Conference on Family Support Related to Disability will be held at the Sheraton Stockholm Hotel in Stockholm, Sweden. For more information, contact: Family Support; c/o Congrex; Box 5619; 114 86 Stockholm. Telephone: +46 8 723 42 30.

LENDING LIBRARY SELECTIONS

The State Developmental Disabilities (DD) Program Office has acquired several education, training and resource materials. **The following materials may be borrowed from the State Office only, located at the address on the front sheet of the State Supplement section of this newsletter. Tel. (612)296-4018.**

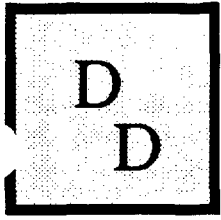
Community-Based Curriculum: Instructional Strategies for Students with Severe Handicaps, Mary Falvey, Paul H. Brookes Publishing Company, 1986. This book is intended to provide educators, parents, and others with strategies for developing and implementing appropriate educational programs for individuals with severe handicaps. The strategies suggested have been used effectively to teach students with severe handicaps to acquire and perform chronologically age-appropriate and functional skills within a variety of integrated community environments. Chapters address: assessment, instructional strategies, skills for living in the community such as domestic, recreation and leisure, vocational, motor, communication, and functional academic skills. The rationale and strategies for developing and implementing educational programs within chronologically age-appropriate regular education schools are delineated. Also included are strategies for moving students and staff from segregated to integrated school sites and facilitating interactions between students with severe handicaps and their nonhandicapped peers.

Gentle Teaching: A Non-Aversive Approach to Helping Persons with Mental Retardation; John J. McGee, Frank J. Menolascino, Daniel C. Hobbs, and Paul E. Menousek; Human Sciences Press, 1987. John McGee described this book best in his introduction: "Gentle teaching is an option to the punishment practices that are commonly used around the world. Those who serve persons with mental retardation with behavioral problems often and noncritically resort to grotesque forms of punishment that in any other situation would be regarded as barbaric and torturous. Gentle teaching is based on a posture that centers itself on the mutual liberation and humanization of all persons, a posture that strives for human solidarity and one that leads care-givers to teach bonding to those who attempt to distance themselves from meaningful human interactions. It focuses on teaching the value inherent in human presence, human interactions, and human reward. It recognizes that all teaching is a community act. If we punish one person, we punish all; if we start to create justice for one, we start to create it for all. Our hope is that we can become teachers of bonding and reward rather than administrators of punishment."

**Metropolitan Council DD Program
300 Metro Square Building
7th and Robert Streets
St. Paul, MN 55101**

*If you no longer wish to receive this newsletter,
please call (612)291-6364, or write to the
DD Program, Metropolitan Council
300 Metro Square Bldg., St. Paul, MN 55101*

(TIME-DATED MATERIAL)



INFORMATION EXCHANGE



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METROPOLITAN COUNCIL DD PROGRAM NEWS

TONI LIPPERT PLANS RETIREMENT--WELL, ALMOST. . .

Guest Writer: Roger Strand

It was a little over 15 years ago that Antoinette (Toni) Lippert began her career as a regional planner in the Developmental Disabilities office at the Metropolitan Council. She plans to "retire" in February. Actually, a better word for it is a "career change" for she hopes to pursue other goals and fulfill unfinished aspirations during the years ahead.

Toni has worn several hats during her career. She and her husband, Bob, who is an English professor at the College of St. Thomas, reared a family of six children. Their involvement in the field of mental retardation started when one of their children, Mary Loretta, (born in 1951) was diagnosed as having severe mental retardation at age four. When Mary was ten years old, Toni and Bob were told by professionals that Mary "would never grow and develop." Since then, Mary has lived at Vasa Children's home; Cambridge Regional Center; Lake Owasso Residence; group homes; and, only recently, an individualized living arrangement under the Home and Community-Based Waiver Program.

Over the years, Toni became a seasoned advocate for her daughter and for others with disabilities. She has served on the board of developmental achievement centers in St. Paul. She has been an active member on many committees and has served on the Board and as President of the Association for Retarded Citizens (ARC) of St. Paul. She served as vice president of the Board of the ARC of Minnesota, and she was one of the founders and eventually served as President of the Minnesota Association for Persons with Severe Handicaps (MNASH). Before she became a planner at the Metropolitan Council, she was the director of the Residential Service Foundation in Minnesota. She also served as a parent representative on the committee that helped to draft Rule 34, the regulations for residential services at the Department of Human Services.

As a planner for the Metropolitan Health Board and the Developmental Disabilities Program, she staffed "1122" and "Certificate of Need" Reviews, which guided the establishment of many new residential programs throughout the seven-county metropolitan area. Council initiatives and publications that she has influenced have affected the development of services in the region and throughout the state, such as: respite care, supported employment, and case management. In

March 1988, three new products regarding case management will be released: **The Case Management Team: Building Community Connections**, consisting of an information booklet; a videotape; and an audiotape.

Toni is probably best known for initiating and publishing this newsletter, **Information Exchange**, which now reaches over 2,600 people throughout the United States and other countries. According to the readers who have called or written, the newsletter is appreciated for providing current, useful information that cuts across all disabilities and many services.

When asked the question during a recent interview with Toni, "Knowing what you do today, what advice would you give to new parents who have a child with a disability?" Toni replied, "Inform yourself about your rights as a parent and your child's rights. This includes what services are **appropriate** for your child and **how** they should be provided. You are the only lifelong advocate for your child, and this requires that you be informed. You should make your views known--even if they differ from other parents, professionals, or advocacy groups. But be open minded and seek **many** sources of information, not just one. My joining the ARC gave me the best source of information, support and built my confidence."

Regarding the question, "What direction should the Metropolitan Council consider taking with regard to the development of policies and plans for the population with developmental disabilities?" Toni replied, "The Metropolitan Council could provide strong leadership for agencies and organizations that will guide them into the next century. What is needed is the **actualization** of the Developmental Disabilities Policy Plan that the Metropolitan Council unanimously adopted in 1985. One excellent model to use in updating the plan is Canada's 'Agenda to the Year 2000.'"

Among Toni's future activities, she includes being part of the effort toward fully integrated services, and the development of residential and training service options that are being considered by the proposed Home and Community Quality Services Act. "What really needs to be done," Toni exclaimed, "is to prepare entire communities for the genuine integration and inclusion of people who happen to have a disability. That is what I would really like to help bring about." So, look out, community. Here she comes!

CORRECTION: The article in last month's issue about the February President's Conference on Mental Retardation inadvertently left out mention of other Minnesotans who have received special invitations to the conference. Dr. Stuart Schleien, Associate Professor, University of Minnesota and Dorothy Skarnulis, Chairperson of the Metropolitan Council's Developmental Disabilities Advisory Committee also participated in the conference proceedings.

824-0708, extension 53.

Adapted Exercise Tapes

Exercise videotapes for people with mental retardation have been produced with advice from the ARC Sar Barbara. They were produced for teenagers and adult and can be used by an individual or by a group. For more information: Special Fitness, Inc.; 4807 Bethesda Avenue, #292; Bethesda, MD 20814; (301) 530-2866.

EXERCISE YOUR RIGHTS!

Don't Complain--Speak Out at your PRECINCT CAUCUS
February 23, 1988

For time and location call: Democratic Party Office
(612) 293-1200
Republican Party Office
(612) 854-1446

or call your local voter registration office.

National Hotline for Questions About Deafness

TRIPOD'S GRAPEVINE is a California-based hotline service for questions about education of hearing impaired children and child development. TRIPOD is a private school for children with hearing impairments with a national advisory board of education experts. The service has extensive resources to obtain up-to-date information for callers. Call 1-800-352-8888 V/TDD.

RESOURCES AND SERVICES

New Resource Directory

The city of Bloomington's Office of Special Services has published a new directory listing the library materials available on loan. These materials include books, magazines, reference publications, films, cassettes and video tapes, educational kits, handbooks, pamphlets and service directories. These resources cover forty-six major disability categories. Purchasers will be sent updated pages to be added to the loose-leaf directory. Contributions of \$11.00 per directory (or whatever people can send) are requested. Make checks payable to the "City of Bloomington"; enclose your mailing address and send to: Resource Library on Disability; City of Bloomington; Office of Special Services; 2215 West Old Shakopee Road; Bloomington, MN 55431. For more information, call (612) 881-5811 or TDD (612) 887-9677.

New Parent Support Group

Pilot Parents in Ramsey County is a new program providing services to parents of children with special needs. The service matches trained, experienced parents with parents wanting one-to-one assistance. Emotional support, general information, introduction to community services and, if necessary, referral to other agencies/service providers are services which experienced parents can offer those in need. Training consists of basic listening skills, stages of family adjustment, limitations of the peer support role, confidentiality, and program policies. Matches are made with consideration to issues involved. The parent desiring service must consent to the match. For more information on the program, contact Jacki Stalley, Family Service Coordinator at 297-6231.

Adult Education Program

Skills for Life, an adult education program for persons with mental handicaps, is offered by Pillsbury House. For a small membership fee of \$2.00, members may take classes such as money management, relationships, aerobics and cooking. Camping, brunches, dances and other recreational activities are also offered. Activities are held on weekday evenings and Saturdays. For more information: Pillsbury House; Skills for Life Program; 3501 Chicago Avenue, S.; Minneapolis, MN 55407; (612)

REQUESTS FOR ASSISTANCE

Conference Helpers Needed

Volunteers are needed to help with the 1988 Annual Minnesota Conference of the Spina Bifida Association of Minnesota, Inc. The conference will be held June 22-25 at the Radisson Hotel in St. Paul. For more information and to volunteer: Pat or Jerry Glisky; SBAM; P.O. Box 29323; Brooklyn Center, MN 55429-0323.

Workshop Presenters Needed

The Parents Advocacy Coalition for Educational Rights (PACER) requests help from parents of young peop' (secondary school age or older) with disabilities to present transition workshops to other parents. A training session will be held in April for volunteers. Please call Christine Hunter or Kris Torma at (612) 827-2966 (V/TDD) or write to: PACER Center, Inc.; 4826 Chicago Avenue, S.; Minneapolis, MN 55417-1055.

Volunteer Drivers

People First, a self-advocacy organization, needs volunteers to drive members to meetings. The meetings are held the third Tuesday of every month in either Burnsville, West St. Paul or South St. Paul. Drivers need not attend meetings. If you can help, please call the Association for Retarded Citizens Suburban at (612) 431-3700.

FUNDS FOR TRAINING AVAILABLE

The United Way of Minneapolis is making training funds available to non-profit health and social service agencies in Hennepin and Anoka counties and parts of Carver, Dakota and Scott counties. The funds may be used for staff attendance at management training classes. Reduced rate classes through the University of Minnesota--Continuing Education and the College of St. Thomas are also provided. For more information call the United Way of Minneapolis, (612) 340-7423.

TRANSITION COMMITTEES MANDATED

Minnesota law now requires all school districts, groups of districts and special education cooperatives to form community transition interagency committees. The

community committees must have representatives from special education, vocational and regular education, community education, post-secondary education and training institutions, parents of students with handicaps, local business or industry, rehabilitation services, county social services, health agencies and other public and private adult service providers.

These groups are reinforced by an interagency agreement signed by the heads of related state agencies. The state agreement defines each agency's specific responsibilities in assuring the appropriate transition of students. A copy of the Executive Summary of the agreement with a chart showing agency responsibilities may be obtained from Debra Olson; Office of Transition; Minnesota Department of Education; 800 Capitol Square Bldg.; 550 Cedar St.; St. Paul, MN 55101.

FOR YOUR INFORMATION

Weekend Retreats for Mothers

The Association for Retarded Citizens of Hennepin County (ARC) invites mothers of a child or adult with mental retardation or a developmental delay to attend a weekend break at Eden Wood Camping and Retreat Center in Eden Prairie, Minnesota. The schedule is planned so mothers of children in certain age groups or having similar needs may meet. **February 12-14** is for mothers of school-age children, **March 11-13** is for mothers of adolescents, young adults or adults, **April 22-24** is for mothers of infants or pre-school children and **May 13-15** is for mothers of children of any age who live away from home and for mothers considering out-of-home placement. Cost is \$45; some financial assistance is available. A registration brochure is available from the ARC Hennepin County; 2344 Nicollet Avenue, S., #370; Minneapolis, MN 55404; (612) 874-6650.

National Epilepsy Center in Minnesota

The National Association of Epilepsy Centers is located in Minneapolis, MN. The new association was organized by leading physicians in epilepsy research, teaching and treatment. The association is designed to complement the activities of existing charitable and scientific organizations and to meet some of the needs not being met by those organizations. Dr. Robert J. Gummit, M.D. of Minnesota is the association president.

Cable Program on Disability

The Minnesota State Council on Disability presents a televised program called **TV Connector**. It is made possible through a grant from the Northstar Chapter of the Multiple Sclerosis Society. The February topic will be, *"Tax Time--Changes in the Tax Law"* and March's topic, *"An Overview of Technology and Persons with Disabilities."* In the Twin Cities the program can be seen on the Twin Cities Regional Cable--Channel 6 and on Continental TV on Tuesday at 6 p.m. Consult your local cable station for viewing time in your area.

American Sign Language College Course

Metropolitan State University offers American Sign Language as an upper division, college credit course.

For more information: Metropolitan State University; 121 Metro Square Bldg.; St. Paul, MN 55101-2189.

Grants for Accessible Vehicles

Under the provisions of Section 16 (b) 2 of the Urban Mass Transportation Act, capital assistance grant funds are available to purchase lift-equipped vehicles for use in transporting elderly and disabled persons.

Administered by the Minnesota Department of Transportation (MnDOT), this grant program is available to private, nonprofit corporations and associations.

The first of seven required application deadlines is February 3, 1988, and the final full application must be submitted by April 13, 1988. To obtain application instructions and information on criteria and requirements, contact MnDOT at (612) 297-2067.

MAP Legal Services

The Management Assistance Project (MAP) is expanding their legal assistance services to Metro Area nonprofit agencies. To answer questions about this service, please contact: Chuck Ravine; MAP Legal Services; 3036 University Avenue, SE; Minneapolis, MN 55414; (612) 623-8309.

Regional Center Moves

The Metro Regional Service Center for people with hearing impairments has moved to the first floor of the Space Center; 444 Lafayette Road; St. Paul, MN. It will share office space with the Department of Human Service's Deaf Services Division.

DEAFNET Computer Communication Network

A computerized communication network for users of TDD can connect people who are deaf with hearing people through a main computer located at the Minnesota Foundation for Better Hearing and Speech (MFBHS). TTYs, TTDs and personal computers with modems can be used to access the DEAFNET Bulletin Board System. For more information: Clarke Christianson, MFBHS; 508 Bremer Building; 7th and Robert Sts.; St. Paul, MN 55101; (612) 223-5136 TDD or (612) 223-5130 V.

MEDIA MASTER LIST TO BE PUBLISHED

The Minnesota State Council on Disability receives numerous calls from individuals, organizations, churches and government agencies requesting information about disability-related film and video presentations which may be available on loan, either free or at a charge. The Council wishes to prepare a master listing of these videos, films and sound/slide presentations which are available throughout the state to use as an information tool for those who inquire.

Send them a listing of all videos, films, and sound/slide presentations which may be borrowed from your media library. Please include the following information: type of media (video, film, sound/slide); length of production; brief description; cost of rental; cost of purchase (if applicable); and the person to contact.

In appreciation for your efforts, the Council will send you a copy of this master list. Send information to Leslee E. Lane; Minnesota State Council on Disability; 208 Metro Square Bldg.; St. Paul, MN 55101.

CONFERENCES/WORKSHOPS

March 5, 1988

A day-long Family Forum for parents, professionals and others concerned about people with developmental disability is being conducted Saturday, March 5, by Association for Retarded Citizens (ARC) of Hennepin County. The event, scheduled for 10 a.m. to 3 p.m. at the Ambassador Hotel at Highways 12 and 100 in Minneapolis, will feature workshops on **early intervention, guardianship and conservatorship, leisure resources, consumer case management, and housing alternatives.** Lunch is included with the \$18 fee for ARC members and \$36 fee for non-members. Respite care is available at another location. For details and registration form, please call for a brochure at (612) 874-6650.

FEDERAL HIGHLIGHTS

Long-Term Home Care Bill for Children with Disabilities

Congress is currently considering legislation that will offer major home care benefits to disabled Medicare beneficiaries, plus extend these same home care benefits to children with **chronic illnesses and chronic disabilities.** H.R. 3436, Medicare Long-Term Home Care Catastrophic Protection Act, is sponsored by Representatives Claude Pepper (FL) and Edward Roybal (CA).

H.R. 3436 is a home care bill for children to age 19, elderly individuals and Medicare beneficiaries with disabilities who are unable to perform, without significant assistance, two "activities of daily living:" eating; dressing; bathing; transferring; or toileting. Technology dependent children would also be eligible for assistance. The following services would be furnished to an individual: case-management services; nursing care; services of a homemaker/home health aide; medical social services; personal care (attendant) services; physical, occupational, speech, respiratory therapy or rehabilitative services to preserve and restore functional capabilities and to prevent further deterioration; medical supplies; durable medical equipment; patient and family education and training and respite care.

Medicare is federally financed with individual contributions obtained through the F.I.C.A. payroll tax on individual incomes up to \$45,000. Medicare has **no state match requirement.** Only individuals having paid into the system through work are eligible for Medicare 2 years after onset of disability or upon obtaining age 65. Under present law, children with disabilities are not eligible for Medicare services unless their parents are recipients. At the present time, Medicare only pays for **acute medical care.** Long-term care, maintenance and

rehabilitation (physical therapy, speech therapy, occupational therapy) are not reimbursable under the present Medicare structure. Rep. Pepper's bill creates a home care system which will serve children with chronic disabilities never before served by Medicare and provide services never before offered through Medicare.

Financing. H.R. 3436 is progressively financed and completely self-funding. The \$23.7 billion benefit package would be paid for by eliminating the cap (\$45,000) on income which is subject to the Medicare payroll tax of 1.45%. This change would impact only 5% of American workers who earn more than \$45,000 individual income, not family income. The Congressional Budget Office (CBO) and the General Accounting Office (GAO) have estimated that the bill will more than pay for itself. In fact, this proposal would contribute over \$2 billion toward reducing the federal deficit next year and over \$6 billion in the next five years.

Advocates expressed concern that the bill did not cover working age individuals that met the eligibility criteria. To address these concerns, Rep. Pepper agreed to add, through demonstration projects (up to 10 projects), home care services for working-age individuals with disabilities who are not social security beneficiaries. The demonstrations will permit a buy-in to the long-term home care benefits with a sliding scale premium based on the average Medicare part A premium.

The bill should be on the House floor now. Members of the House of Representatives need to hear from families with children with disabilities about the importance of home care both for children and adult dependents. Explain how important long-term home care services are to your family and that, in most cases, the alternative is costly institutional care away from family and friends. It is important that individual letters reflect personal benefits of home care for families with eligible dependents. All members of the House can be reached by writing: The Honorable _____; U.S. House of Representatives; Washington, D.C. 20515. **This bill is different from H 1673, Home and Community Quality Services Act.**

(This article was adapted from information in Word from Washington, published by United Cerebral Palsy Associations, Inc.)

Proposed Tax Incentives for Employers of People with Disabilities

Senator Tom Harkin (D-IA), Chairman of the Senate Subcommittee on the Handicapped, introduced legislation that would amend the Internal Revenue Code of 1986. This bill, S. 1806, would "allow the costs of property designed specifically for handicapped and elderly individuals as a trade or business deduction."

The bill would allow a company that must purchase equipment in order to accommodate a current or prospective employee who has functional limitations on the job to claim a business deduction on that purchase. S. 1806 was co-sponsored by Senators Lowell Weicker (R-CT), Robert Dole (R-KS), Paul Simon (D-IL), Spark Matsunaga (D-HI) and Donald Riegle (D-MI). The bill has been referred to the Senate Finance Committee, where it awaits further action.

INFORMATION EXCHANGE

STATE
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Developmental Disabilities
Councils

February 1988

RICHARD SHATTMAN PRESENTS VERMONT'S SCHOOL INTEGRATION MODEL

"The process of reversing current segregation of special education students in public schools is dependent upon the creation of an environment which fosters shared responsibilities and collaborative planning, and is based upon a strong commitment to values--essentially, that all children are capable of learning." Speaking before the Special Education Advisory Committee of the Minnesota Department of Education on January 14, 1988, Richard Shattman, Director of Special Education of the Franklin Northwest Supervisory Union in Swanton, Vermont, stressed the importance of establishing a common set of principles or values as the foundation of working toward "Full Integration: A Means to the Intent of Least Restrictive Environment," the title of his presentation.

It may have taken his regional planning committee three years to agree upon a set of principles, but once they had concluded that all children can learn, and that they learn best among their peers who are not necessarily handicapped, the conceptualization of Vermont's "Homecoming Model" fell into place. For the past five years, the staff of the Homecoming Project, along with the administration and instructional staff of 26 schools, have developed, field-tested, and evaluated a model to bring "home" students from regional special education programs and prevent other students from ever being placed in them. This model has been adopted by, and is fully operational in, four supervisory unions across Vermont.

The Homecoming Model is based upon the concept of "shared ownership" among regular and special educators for the education of students with challenging needs within regular classrooms in local public schools. Their experiences have borne out the wisdom behind the thoughts of Madeleine Will, Assistant Secretary for the Office of Special Education and Rehabilitative Services, U.S. Department of Education:

If we are to correct the flawed vision, to refine the vision, not obliterate what is good in present vision, not destroy what we have worked so hard to achieve, then an atmosphere of trust will have to be created. Success will mean constant input from parents, administrators, teachers, and state and local governments. It will mean acceptance of the general applicability of special education techniques beyond the confines of the special education class. Success will mean the creation of a more powerful, more responsive education system, one with enhanced component parts. It does mean that special programs must be allowed to use their knowledge

base and services to prevent students with learning problems from reaching the point of failure in the educational system. (**Exceptional Children**, February 1986, p. 413)

The Homecoming Model utilizes a building-based planning team process and a consultative approach for the provision of services to all students with severe handicaps. Integrated services are provided to all students regardless of the nature and severity of the child's disability. The glue that holds this integration model together consists of three basic desired student outcomes: 1) positive self-image, 2) positive social skills, and 3) development of higher level of cognitive skills. Some of the advantages of integrated educational settings include:

- Students benefit from the collaborative planning of parents, regular and special educators, and administrators. (Integrated services need this collaboration to work.)
- Teachers on planning teams report:
 - They have more meaningful input with student programs.
 - Building level expertise is used more creatively on teams.
 - Administrators are more supportive and better able to assess the need for additional resources when recommended by a team of professionals and parents.
- Parents on planning teams report:
 - They are more interested in meeting frequently to plan with the school than once or twice a year at individual education plan (IEP) meetings.
 - They are more comfortable interacting with staff from their local school than the Area Program teachers.
- There is no instructional time lost to transportation. (Many students previously spent as much as an hour and a half getting to their special building in the morning by bus.)
- Students learn more and faster in integrated settings, and what they learn is more easily generalized to settings where there are children who do not have handicaps.

Shattman suggested several activities for the development of state level policy on integration:

1. Encouragement of a process for the development of local philosophy (guided by principles of a unified school system).
2. Development of a long-range plan (5 to 10 years) guided by an articulated philosophical base and specific details relative to intermediate stages and transition.
3. Development of model programs throughout

- different regions of the state.
4. Development of specific policy directing the nature of how funded programs may serve children with severe handicaps. Policies should address: funding, staff development, curriculum, and placement/review of student programs outside the community school setting.
 5. Monitoring practices should be guided by principles of integration.
 6. Local school districts should develop a local education agency plan (LEAP) for the state detailing a plan of action for the provision of integrated services (which serves as a basis for monitoring).
 7. Provide leadership to universities in the area of teacher and teacher aide preparation.

Shattman provided several handouts on integration. One, in particular, is extremely helpful, **Best Educational Practices 1986: Educating Learners with Severe Handicaps**, Center for Developmental Disabilities, University Affiliated Facility Satellite, University of Vermont. Copies are available upon request from: Minnesota Governor's Planning Council on Developmental Disabilities; 300 Centennial Building; 658 Cedar Street; St. Paul, MN 55155. Tel. (612) 296-4018.

Hearing Examiner Issues Ruling in Moundview School District

On January 21, 1988, a decision was made by the state-appointed hearing examiner, Susan Weisman, that a nine-year-old girl, Molly Pessar, with severe mental retardation, be permitted to attend the third-grade class in her own neighborhood school in Shoreview. Molly had been attending a special education classroom in New Brighton. This placement was appealed by her parents last fall.

"Molly needs to learn to interact as effectively as possible with all people in her environment, handicapped and non-handicapped, now and in the future," Weisman wrote. She added, "It is important that members of Molly's community learn to interact as effectively as possible with her." For more information, contact Larry Ringer, Attorney, DD Legal Advocacy Program; (612) 338-0968.

APPLICATIONS SOUGHT FOR PARTNERS IN POLICYMAKING

The Minnesota Governor's Planning Council on Developmental Disabilities is currently seeking applications for participation in Partners in Policymaking. This program is a one-year leadership training program designed to give participants skills to change the quality of life for people with developmental disabilities. This training is intended for interested young parents of individuals with developmental disabilities or people who are themselves disabled.

The Governor's Planning Council on Developmental Disabilities recognizes that well-informed parents and individuals with disabilities have historically had a powerful influence on policymaking by elected and

appointed governmental officials. Partners in Policymaking can enhance knowledge and sharpen the skills necessary to have an impact that will benefit individuals and all people with disabilities.

This search actively seeks both males and females, members of minority communities, people who represent individuals with all types of disabilities which are severe, and participants from all parts of the state. Expenses are paid for travel, lodging, meals, and respite care.

Selection will be made based on the quality of the applications. Applications are due on March 31, 1988. Final selection will be made by April 15, 1988. The first session will be held on May 13 and 14, 1988. Attendance at all sessions is mandatory. Please direct requests for applications to: Governor's Planning Council on Developmental Disabilities; 300 Centennial Office Building; 658 Cedar Street; St. Paul, MN 55155. Tel. (612) 296-4018.

SUMMARY OF ADVISORY TASK FORCE MEETING--NOVEMBER 9, 1987

Members of the Commissioner's Advisory Task Force on Mental Retardation and Related Conditions of the Department of Human Services (DHS) has requested that brief summaries of their meetings be reported in **Developmental Disabilities Information Exchange -- State Supplement**. This Advisory Task Force meets bimonthly and acts upon those issues presented by various work groups and departmental staff members. Following is a summary of their meeting held on November 9, 1987: The Case Management Work Group submitted their report. Their conclusions and proposed recommendations were:

1. Counties should be given information on how to maximize waiver funding for case management services. Stearns County has used waiver funding in very creative ways to improve caseload ratios.
2. DHS should seek and/or support legislative authority to amend the state Medicaid plan to include case management for persons with mental retardation and related conditions. In a recent survey by the University Affiliated Program, 58 of 60 county directors supported this change. Additional resources should be sought from the Legislature to ensure acceptable case management caseloads.
3. DHS and other agencies should promote positive stories about good case management. Effective case management can save public funds.
4. Further study is needed to determine the degree to which duplication of case management functions exists. Social workers and case managers are employed by regional treatment centers, community ICF-MR providers, community day programs, public schools, HMOs, and public health programs. If duplication exists, funding could be reallocated from these positions to counties.
5. DHS in cooperation with other agencies should develop, conduct, and evaluate a long-range program of preservice and in-service training for case managers. All recommendations related to

training submitted by the Quality Assurance Subcommittee are also endorsed.

Richard Cohen emphasized that more funding and more resources are needed for case management. The current ratio of clients to case managers is not acceptable.

Ed Skarnulis announced that a series of 15 training sessions are being presented by DHS around the state on case management. While this will not substitute for the level of training needed, it will address some of the concerns expressed by the case management work group. Furthermore, DHS has conducted time studies in the counties and has channeled additional money for case management.

Bill Hendrickson suggested that recommendations be added to the report on case management regarding preservice and in-service training. The report was accepted with this amendment. After the report is finalized, it will be sent to the Commissioner after the January meeting.

Anne Henry presented the Quality Assurance Work Group's report. She stated that Minnesota lacks a comprehensive system to assure quality services. The work group identified and analyzed 12 types of possible reviews. The work group's goals are: 1) to have all 12 levels of quality assurance review operate effectively in Minnesota, and 2) to have a single independent office which could collect, disseminate, and investigate information on the quality of services from all levels of quality assurance activity.

The information collected would be used by DHS to reward successful efforts, develop action plans for improvement, provide training and other incentives for change, and impose sanctions for unacceptable performance. The quality assurance system would provide public access to information without jeopardizing privacy. The outcome of such an effort would be an improved service system designed to meet individually identified needs for persons with developmental disabilities in the least restrictive manner through the responsible use of resources.

Richard Cohen commented that there are so many quality assurance checks in place that it seems counterproductive. He suggested eliminating duplication to free up time and money for more productive activities. The report as submitted was approved by the Committee members and it will be sent to the Commissioner with a response requested.

Dennis Theede gave a brief update of the Training Work Group's activities. The group has identified funding as a crucial issue in the provision of training. The group is critiquing a study done for DHS by an independent contractor on the subject of training. The group expects to develop and endorse some fundamental training requirements for persons who work with persons with developmental disabilities. Written recommendations will be developed by the group in December.

For more information and/or a copy of the minutes, contact: Tom Fields; Division for Persons with Developmental Disabilities; Department of Human Services; Space Center Building, 4th Floor; 444 Lafayette Road, St. Paul, MN 55101. Tel. (612) 296-2147.

PUBLICATION

ARC Facts: Family Support, Jerry Adams, Association for Retarded Citizens of the United States, November 1987. This is an information sheet which outlines the broad scope of support services to families that may be needed to help a family member with a disability to stay at home rather than live in housing provided through federal and state programs. Family support services are designed to supplement existing programs, not replace them, such as respite care, crises intervention, child care, information and referral, architectural changes of home, medications, counseling, recreation activities, transportation, cash subsidies, and a host of other services. An annotated bibliography is available to learn more about family support services. For a copy of this fact sheet and other fact sheets, contact: ARC; National Headquarters; 2501 Avenue J; Arlington, Texas 76006. Tel. (817) 640-0204.

A STORY THAT I HEARD

The following selection is from **A Story That I Heard: A Compendium of Stories, Essays, and Poetry about People with Disabilities and American Life**, collected by David B. Schwartz, John McKnight, and Michael Kendrick, published by the Pennsylvania Developmental Disabilities Council, 1987:

THE DIGNITY OF RISK Betty Pendlar¹

As a parent, I learned a great lesson on the dignity of risk from my daughter's teacher in a special school when Lisa was only four years old. This was a school run by our local chapter of the Association for Retarded Children. One day I got a note requesting that I send a plate and a knife to school with Lisa. The note emphasized that it must not be plastic, but a real plate and knife. I gasped in horror, envisioning what would happen to my little darling, but I dared not refuse because I wanted her in this program.

Two weeks later, the parents were invited for lunch. There I saw the group of students cutting up celery, tomatoes, etc. I asked the teacher if she had the same fear I had--that these little ones would cut themselves. She replied, Of course, it can happen, but I watch carefully. And if it should happen, I would give everyone a lesson in what blood looks like.

That started me on the road to allowing Lisa to do all kinds of chores around the house, so I am very grateful to that teacher.

¹ Betty Pendlar lives in New York City, is retired, and spends her time with advocacy issues. Lisa, who has Down Syndrome, lives in a community residence in New York City.

LENDING LIBRARY SELECTIONS

The State Developmental Disabilities (DD) Program Office has acquired several education, training and resource materials. **The following materials may be borrowed from the State Office only, located at the address on the front sheet of the State Supplement section of this newsletter. Tel. (612)296-4018.**

New Perspectives on Down Syndrome, S.M. Pueschel, C. Tingey, J.E. Rynders, A.C. Crocker, & D.M. Crutcher (Eds.), Paul H. Brookes Publishing Company, 1987. This book is the result of a state-of-the-art conference held in Boston, Massachusetts, April 23-25, 1985, sponsored by the Office of Special Education and Rehabilitative Services in cooperation with the National Institute of Handicapped Research, and National Down Syndrome Congress. Purpose of the conference was to sharpen issues and present cutting edge information and research findings from biomedical, educational, psychosocial, and community living perspectives. This book is not intended to be totally comprehensive but rather addresses many of the most pertinent aspects of life span issues surrounding Down Syndrome, as well as to offer research recommendations.

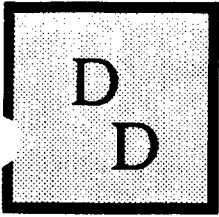
The Nonrestrictive Environment: On Community Integration for People with the Most Severe Disabilities, S.J. Taylor, J.A. Racino, J.A. Knoll, & Z. Lutfiyya, Human Policy Press, 1987. This book is a product resulting from the Community Integration Project at Syracuse University, designed to provide technical assistance and disseminate information on model programs and practices for serving people with the most severe disabilities in integrated community settings. The authors state that for the past decade and a half, the concept of "least restrictive environment" has been a guiding principle for services for people with disabilities. As the state of the art evolves, however, this principle is gradually giving way to a new one: what might be termed the principle of nonrestrictive environment. The nonrestrictive environment does not restrict or regiment. The nonrestrictive environment is not a homelike facility. It is a home; supports and services may need to be built in, but it is a home nonetheless. The challenge is to create a network of humane, effective, and integrated services in the community for all people with developmental disabilities.

**Metropolitan Council DD Program
300 Metro Square Building
7th and Robert Streets
St. Paul, MN 55101**

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INFORMATION EXCHANGE



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METROPOLITAN COUNCIL DD PROGRAM NEWS **1988 AGENDA: REALIZING THE VISION**

(Editor: Toni Lippert)

In a rare departure from the traditional style of this newsletter, I would like to address its readers in a personal message. It has been my privilege, as the Metropolitan Council planner for the DD Program, to assist in shaping the Council's regional policies for persons with developmental disabilities. I have also been involved in other activities: technical assistance, coordination and information dissemination.

Perhaps no other aspect of my work has given me as much personal satisfaction as the publication of the **DD Information Exchange** for the past 13 years. I truly believe that comprehensive and accurate information is the most important element needed by consumers, providers and policy-makers to make wise decisions in judging both services and their outcomes and in keeping current with the amazing new things that are being learned almost daily about persons with developmental disabilities.

Occasionally some of you have called me to tell how valuable the newsletter is to you. Those communications have been a source of deep, personal satisfaction as I sit, month after month, scouring dozens of other sources to bring you news that applies to the whole range of disability categories, across all sectors of service and readers--individuals with developmental disabilities, their family members, direct-care and supervisory service providers, consumer organizations, governmental agencies and those who are responsible for related laws and regulations.

I want to thank each reader for inspiring the production of this newsletter. I am convinced that future issues will continue to be valuable and any changes will undoubtedly be improvements.

Kay Zwernik, the Metropolitan Council's new Senior Planner for the developmental disabilities program, brings outstanding credentials to this position. Although she is well known in Minnesota, a brief overview of her past experience will allow other newsletter readers to

share the high expectations with which I transfer my responsibilities to Kay.

Kay has twenty years of work experience in the field of developmental disabilities in direct care, administering programs, and in consulting and volunteer work. Her experience crosses all the major service sectors: DAC (pre-school and adult), sheltered workshop, special education, legal advocacy, recreation, residential and case management.

She has held memberships in numerous consumer and professional organizations including the ARC, CEC, AAMD, TASH and was a founding member of MNASH. One of Kay's most successful accomplishments was developing a three-year training program for direct care staff and administrative staff of community provider organizations. The project curriculum first introduced participants to many of the integration philosophy principles. Recently Kay has been providing consultation on a county case management project. After a twelve-year friendship with a woman who is mentally retarded, Kay Zwernik became her legal guardian in November, 1987.

The developmental disabilities program is sure to grow stronger under Kay's direction.

HOME MODIFICATION PROGRAM AVAILABLE

Courage Center recently launched a new home modification program for people with physical disabilities who want to adapt their homes to make them more accessible. The Home Modification staff are professionals in the field, and knowledgeable in the areas of accessibility, building codes, construction and in obtaining funding sources.

The staff works with clients to assess their individual needs. This includes deciding what changes are appropriate--such as installation of grab bars, ramp systems, or room layout changes. The program also provides for help in locating funding sources and contractors familiar with home modification, and for monitoring construction. For further information about the home modification program, write: Shannon McGurran; Courage Center; 3915 Golden Valley Road;

Activities, notices, services, products, etc. mentioned in this publication are for information purposes only and do not imply endorsement by the Developmental Disabilities Programs of the Metropolitan Council and the State Planning Agency.

Golden Valley, MN 55422; (612) 588-0811, extension 518.

FOR YOUR INFORMATION

Seeking Effective Leadership

PACER would like to begin a regular dialogue (via meetings, phone calls, or correspondence) with regular education elementary principals about the integration of students in special education who have been or will be placed in programs in regular education buildings.

If you know of a principal who is effective in communicating with parents of children with special needs, interested in the design of programs for special education students in regular education settings, or, in your opinion, would probably be positively and constructively involved if integration programs were underway in her or his building, please write PACER a letter with the principal's name and school address and an explanation of why you feel the person you are nominating would be a good addition to PACER'S proposed dialogue. Write or call PACER Center, Inc.; 4826 Chicago Avenue S.; Minneapolis, MN 55417-1055; (612) 827-2966 V or TDD.

Publications on Community Integration

The Center on Human Policy at Syracuse University has a Community Integration Project and Research and Training Center. The Center has developed a comprehensive collection of reports and resources on integration of people with severe disabilities into community life. The Center will send a list of these publications which are offered for the cost of reproduction and postage. This list is a "must" for all readers concerned with integration concepts and practices. Request the list from: Center on Human Policy; Syracuse University, Community Integration Project; 724 Comstock Avenue; Syracuse, NY 13244-4230.

Board Recruiting and Training

Management Assistance Project (MAP) is offering a new publication on board member recruiting and training for non-profit organizations. The booklet, **Joining the Board of a Non-Profit Organization** covers a variety of very useful topics: role of the board and individual board members, liability, fund-raising and advantages of corporate volunteer members. The appendices cover statutory and other relevant matters. The booklet and postage cost \$3 or \$2.50 for ten or more copies. Order from: MAP; 3036 University Ave. SE; Minneapolis, MN 55414.

Head Injury Toll-Free Information

The National Head Injury Foundation is launching a national public education effort on traumatic head injury. Called **Project TAP** the program will develop and distribute information for families, the injured person, professionals and the public. **Project TAP** has a toll-free

line for assistance and information: 1-800-444-NHIF.

Theatre Workshop for Youth With Hearing Impairments

"Theatre Workshop for Teenagers" will be taught by George Sand and Billy Yount. Billy Yount is a well-known actor who is deaf and a wonderful role model for youth. Workshop includes exploration of emotions, attitudes and real-life roles as they are transferred to visual theatre. Class is Saturday, April 2, 10 a.m. - 2:30 p.m. Cost is \$15. Bring bag lunch. To register: make check payable to Northern Sign Theatre, and send to Northern Sign Theatre; 1517 E. Lake St., Suite M-3; Minneapolis, MN 55407. Phone is (612) 729-2837 V/TDD.

Scuba Diving, Anyone?

The Handicapped Scuba Association is a nonprofit organization that specializes in teaching scuba diving to people with all types of physical disabilities. Diving is especially appropriate for people who are hearing impaired because the language of the sport involves manual symbols. HSA has a captioned film, "Freedom in Depth." It documents the progress of 19 divers from pool training to Colorado River rapids to exploring a sunken ship. If you would like more information on this organization or its programs, contact the Handicapped Scuba Association; 1104 El Prado; San Clemente, CA 92672.

N.O.D. Newsbits

The following items from the National Organization on Disability's newsletter may give readers some useful ideas:

WASHINGTON COUNTY, PA. Peoples Natural Gas Company is offering a specially designed thermostat for customers who are blind or visually impaired to enable them to determine temperature settings for their furnaces. The raised thermostat is available at no charge, and settings on oven and range controls are also specially marked. Contact: Dan Huffman; N.O.D. Liaison, Assistant Director for Human Services for Washington County; 503 Courthouse Square; 100 W. Beau St.; Washington, PA 15301.

NEW YORK, NY. Mayor Ed Koch has signed accessibility legislation which requires that new construction and rehabilitated buildings be made accessible and adaptable for people with disabilities. The law includes references to wider doorways, bathroom and kitchen modifications such as mirrors, outlets, cabinets, counters, sinks and other features. Contact: Carol Ann Roberson; Mayor's Office for the Handicapped; 52 Chambers St., #206; New York, NY 10007; (212) 566-0972.

TULSA, OK. Mayor's Commission on Concerns of the Disabled joined with the Tulsa Metropolitan Ministry to conduct a survey of more than 500 Tulsa churches and synagogues to determine services offered to persons with disabilities. Supporting the concept that persons

with disabilities are not seeking "separate but equal" religious programs but rather mainstreaming into the activities of the congregation as a whole, the focus of the effort was to "move beyond 'ramps' per se to the arena of attitudes and acceptance." Contact N.O.D. Liaison, Constance Teter; Chair, Mayor's Commission on Concerns of the Disabled; 1700 A. Utica Sq. #174; Tulsa, OK 74114; (910) 493-8498.

Speaker's Bureau

The Association for Retarded Citizens Suburban volunteer speakers bureau is available to community organizations, schools or youth groups in the Dakota, Scott and South Washington county areas. Speakers will present information on mental retardation and show the new video *A New Way of Thinking* produced by the Governor's Planning Council on Developmental Disabilities.

A New Way of Thinking tells the story of five people with developmental disabilities, focusing on human needs like dignity, respect, family, real home, friendship, opportunities to learn and grow, and contributing to society, rather than special needs. One of the people featured in the video is Tommy, a three year old from Burnsville. Tommy's family agreed to participate in the video because they wanted people to know that "even though they have a child with multiple disabilities, they work hard to have a normal life and it's worth it." They hope that the community will gain "a better awareness of children and adults with handicaps and of disabilities general."

The video also features Nina, a 13 year old girl who, through her school program is developing friendships and learning functional skills to work and participate in the community; Frank, a young adult working in the community; and Diane and Suzanne whose living arrangements have been tailored to meet their individual needs. The video ends with a quote from Hubert Humphrey: "The time has come when we can no longer tolerate the invisibility of the handicapped in America...These people have a right to live, to work and to the best of their ability--to know the dignity to which every human being is entitled."

DD Amendments Signed Into Law

President Reagan signed into law P.L. 100-146, the Developmental Disabilities Assistance and Bill of Rights Act Amendments of 1987. This legislation extends the four components of the Act (State Grant, Protection and Advocacy Systems, University Affiliated Programs and Projects of National Significance) through fiscal year 1990. The major changes to the Developmental Disabilities State Council operations of interest to the ARC are state planning requirements which require the State Council to conduct a comprehensive review and analysis of eligibility for and effectiveness of services by state agencies for all persons with developmental disabilities. The review must include a survey of consumer satisfaction of the services and public forums must be held to present the findings of the review and obtain comments on any Council recommendations. The

Council must, by January 1, 1990, recommend to the Governor the most appropriate state agency(ies) to be designated as responsible for the provision and coordination of services for persons with developmental disabilities who are traditionally unserved, those who have a combination of physical and mental impairments and other subpopulations as identified by the Council. The new law also requires a review of the Developmental Disabilities program's state administering agency.

RESOURCES/SERVICES

Announcing New Early Intervention Quarterly

Your Link is a new quarterly published by the Interagency Planning Project for Young Children with Handicaps. It features current information about Minnesota's efforts to successfully implement a "family-driven early intervention system" for infants and toddlers with handicaps or at risk and for their families. To get on the mailing list for the free newsletter, call or write: **Your Link**; IPPYCH; 8th Floor, Capitol Square Bldg.; 550 Cedar St.; St. Paul, MN 55101; (612) 296-7032.

PACER Free Workshop Guide

The Parent Advocacy Coalition for Educational Rights (PACER) has a brochure on its free winter workshops for parents of children and young people with disabilities. To request a copy write or call: PACER Center; 4826 Chicago Avenue S.; Minneapolis, MN 55417; (612) 827-2966 V/TDD.

Consumer Case Manager Leadership Training

The Association for Retarded Citizens Suburban is offering a leadership training series to empower consumers, family members and guardians to take primary roles in case management services:

- **March 19, 1988** topics include: "*Personal Meaning of Consumer Case Management*", "*What is Minnesota Case Management (Rule 185)*", "*Who's in Charge*".

- **March 26, 1988** topics will be: "*Waivered Services and How to Monitor Services*", "*Community Resources and You*", "*Writing Goals and Objectives*", "*A New Way of Thinking*", "*Making Connections*".

All sessions will be held from 8:30 a.m. to 3:30 p.m. in the United Way Multi Service Center; Community Action Council Building; 14451 County Road 11; Burnsville, MN. Registration fee for ARC members is \$20 and \$44 for non-members. Fee includes lunch. Call Marijo McBride to register: (612) 431-3700.

RECREATION/LEISURE

Camp Hand in Hand 1988 Schedule

Camp Hand in Hand will offer two camping sessions next summer for individuals with autism. The sessions are scheduled for July 31 - August 6 and August 7 -

August 13, 1988. For more information: Twin Cities Society for Children and Adults with Autism; 253 E. Fourth St.; St. Paul, MN 55101; (612) 228-9074.

Winter Wonders

A three-day adventure weekend is being offered by Wilderness Inquiry II March 11-13, 1988. This sixth annual "Access to Winter Weekend" will take place at the Environmental Learning Center in the Superior National Forest near Isabella, Minnesota. Cost for lodging, meals, equipment, all activities and staff is only \$70 per participant. For further information about this weekend or any of their programs, call (612) 379-3858 V/TTY.

Matching Vacations

Are the folks living in group homes interested in visiting traditional tourist spots like Disney World, the Grand Canyon or Yellowstone National Park? You bet! But many cannot afford vacations due to the combined expenses of air travel, lodging and van rental.

Two counselors from South Norfolk County Association for Retarded Citizens in Norwood, MA think residents of group homes deserve a vacation like anybody else. Celeste Caffey and Richard Tung are developing a computerized service that will match a group from one residential program to a similar program in another state. The two groups then trade vacations.

For example, if residents of a group home in New Jersey wanted to visit California, Caffey and Tung would feed information about the group into a computer, which matches the New Jerseyans with a group home of similar characteristics in California. Provided the Californians wouldn't mind visiting the myriad of New Jersey's attractions, the groups would alternate having each other as guests, share resources and eliminate van rental and motel costs. That only leaves air fare as the major expense.

Interested residential programs or MR-related organizations can find out more by contacting Caffey or Tung in care of the South Norfolk County Association for Retarded Citizens; 18 Clapboard St.; Norwood, MA 02062; (617) 762-9598.

Summer Camp and Retreat Opportunities

Eden Wood Camping and Retreat Center has announced its schedule for summer and fall 1988 activities. For adults there are one-day to one-week sessions including such topics as creative arts, canoeing, sports and health, leisure specialties, and more. Adult trips and vacations to such places as Yellowstone National Park, Memphis and Graceland, the Wisconsin Dells or a cabin up north are offered. Similar programs are offered for children between the ages of 5 to 18. For further information on dates and costs contact: Eden Wood; 2344 Nicollet Avenue S., #370; Minneapolis, MN 55404; (612) 874-6650.

PUBLICATIONS

■ **Beyond the Threshold: Families Caring For Their Children Who Have Significant Developmental Disabilities.** 1986. Kathleen McKaig, Francis G. Caro and Michael J. Smith. 62 pp. \$5.00. This publication explains how the public should provide the special supports needed by families who care for their developmentally disabled children at home. The unique support system proposed, which combines case advocacy with a voucher plan, was created after listening to the needs of families who have taken on this challenge.

■ **Caring for the Developmental Disabled Child at Home: The Experiences of Low-Income Families.** 1987. Michael J. Smith, Francis G. Caro, Kathleen McKaig. 75 pp. \$6.00. This is one of the first studies in the United States which gives explicit details of the care that low-income parents give to their developmentally disabled children. The stories of these parents, told in their own words, relate the extraordinary challenge of this task. This is essential reading for all concerned with the issue and especially those planning family support programs.

■ **Supporting Families Who Care for Severely Disabled Children At Home: A Public Policy Perspective.** Francis G. Caro and Susan Cina. 1984. 77 pp. \$6.00. The paper makes the case for stronger public policies to assist families in providing basic care to their developmentally disabled children. Existing measures which assist families are reviewed; policy options for strengthening caregiving capacity of families are identified.

Send checks payable to: Community Service Society; Office of Information; Dept. of Public Affairs; 105 E. 22nd St.; New York City, NY 10010. Costs include postage.

Guidelines for Bias-Free Publishing, a 38 page booklet with guidelines for fair representation of persons with disabilities in print, published by McGraw-Hill Book Company. \$2.00. McGraw-Hill Distribution Center; Princeton Rd.; Hightstown, NJ 08520.

Tips for Hospitality, a brochure for restaurateurs who want to make their establishments accessible to persons with disabilities. Single copy free. Both available along with a publications catalog from National Easter Seal Society; 2-23 W. Ogden Ave.; Chicago, IL 60612; (312) 243-8400, ext. 154 or TDD (312) 243-8880.

The President's Committee on Employment of the Handicapped has published a series of brochures to help employers "**Respond To**" workers with disabilities. For free copies and a publications list contact The President's Committee on Employment of the Handicapped, Attn: Research and Publications Dept.; 111 - 20th St., NW, Suite 636; Washington, DC 20037 (202) 653-5044.

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Member of
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Councils

March 1988

OREGON STUDY CONCLUDES: "PEOPLE WHO LEFT FAIRVIEW TRAINING CENTER ARE LIVING RICHER LIVES"

A study was recently conducted in the State of Oregon which provided a post-hoc analysis of the lifestyles of 327 people who moved from Fairview Training Center to community living settings between 1984 and 1986. This study joins a host of other studies over the past 15 years that have overwhelmingly supported community-based living. However, this study is one of few that considered the activity patterns of the people who moved to community settings in addition to combining an analysis of other variables: family perceptions, social integration, physical integration, variety, and adaptive behavior. The report is entitled, **An Activity-Based Analysis of Deinstitutionalization: The Effects of Community Re-entry on the Lives of Residents Leaving Oregon's Fairview Training Center**, written by Robert H. Horner, Susan K. Stoner, and Dianne L. Ferguson of the University of Oregon.

Most of the 327 people who moved from the Fairview Training Center over the three years covered by this study were adults, but there were children as young as age 9, and individuals as old as 74 who participated in the move. The people who moved evenly represented all levels of disability, mild, moderate, severe, and profound.

Study results indicated that people who returned to the community became active members of the community. "Interpretation of the activity pattern, social network, adaptive behavior, and family perception data provided a clear and consistent message," the authors stated. "The people who left Fairview are living richer lives than if they had remained in Fairview. They experience more diversity, more community contact, more social contact, and more adaptive behavior than matched peers currently in Fairview." "In addition," the authors continued, "family members associate the community move with people seeming 'happier.'" Four issues for future consideration were identified by the researchers:

1. Reinstitutionalization had been experienced by 23 percent of the people observed over the three-year period. Not only was there incomplete information obtained by the service providers on the reasons for reinstitutionalization, but there were apparent gaps in the support services that were provided in the community. "One of the concerns associated with community re-entry should be access to adequate medical support," the authors

recommended.

2. Residential support in Oregon had been characterized by service "models," such as 10-bed and 5-bed facilities. "The substantial variability in the activity patterns, levels of support, and social networks of the people who receive residential support suggest the need for greater flexibility in the design and structure of residential support services," the authors suggested.
3. Since family members pose the most consistent and the largest social network subgroup, serious concern should be given to assisting people to re-enter the community near their families when this option is possible and feasible.
4. While significant supports are provided to people as they pursue their lives in the community, there was not an indication that the extensive level of support needed by people with the most severe disabilities was being delivered. "The results do not suggest that those persons with more challenging medical and/or behavioral demands have participated in Oregon's deinstitutionalization effort to date," the authors observed.

"While the data suggest a need to increase the range of supports available in the community, the results clearly indicate that every effort should be made to continue and extend the policy of assisting people who are leaving institutions to re-enter their local communities," the authors concluded. A copy of the report may be requested from: Center on Human Development; Clinical Services Building; College of Education; University of Oregon-Eugene; Eugene, Oregon 97403, Tel. (503) 686-3591.

INVITATION

The Governor's Planning Council on Developmental Disabilities invites you to a reception for Toni Lippert on the occasion of her retirement.

Wednesday, April 6, 1988

Earle Brown Center

UM-St. Paul Farm Campus

2:30 - 3:30 p.m.

MARCH 1988 IS DEVELOPMENTAL DISABILITIES AWARENESS MONTH

The Administration on Developmental Disabilities in Washington, D.C., is encouraging each state and territory to observe March 1988 as Developmental Disabilities Awareness Month. The theme for 1988 is "Community, a place where people...earn, learn, come and go, and live fuller lives." "It is, after all, in each community where attitudinal barriers exist that affect everyday life for people who have developmental disabilities," administration officials commented in a recent letter. It is in our communities where change can be created--the change that occurs when fears and old attitudes are replaced with information and understanding.

A limited supply of materials developed by the Ohio Public Images, Inc., are available from the Governor's Planning Council on Developmental Disabilities office:

1) posters (which may be picked up at the state DD Office); 2) book markers (available through the mail); and 3) **A Public Awareness Guide for Developmental Disabilities Awareness Month** (available on a loan basis). For more information, call: (612) 296-4018.

"A NEW WAY OF THINKING" VIDEOTAPE RELEASED

As a major activity planned for observing March 1988 as Developmental Disabilities Awareness Month, the Minnesota Governor's Planning Council on Developmental Disabilities, in cooperation with the Minnesota University Affiliated Program, has produced and distributed copies of a videotape named after the publication, **A New Way of Thinking**. Hundreds of copies of the videotape have been distributed within Minnesota, to all states and territories, and to several countries.

A New Way of Thinking videotape tells the stories of five Minnesotans with developmental disabilities and their families. Focus is upon the importance of basic human needs (rather than special needs) such as dignity, respect, family, having a real home and a real job, friendships, and being a contributing member of society. The 20-minute tape ends with a quote from Hubert Humphrey: "The time has come when we can no longer tolerate the invisibility of the handicapped in America...These people have a right to live, to work, and to the best of their ability, to know the dignity to which every human being is entitled."

A copy of this videotape (1/2 inch VCR) may be borrowed from: Governor's Planning Council on Developmental Disabilities, State Planning Agency, 300 Centennial Office Building, 658 Cedar Street, St. Paul, MN 55155. Tel. (612) 296-4018.

PARTNERSHIP FOR QUALITY SERVICES EXPANDS; VIDEOTAPE AVAILABLE

The volunteer monitoring project called Partnership for Quality Services has begun its second year of operation

by the Association for Retarded Citizens of Minnesota with funding by the Governor's Planning Council on Developmental Disabilities. Volunteers have been trained in four communities: Hennepin and Dakota counties, Duluth, and Mankato/New Ulm. The volunteer monitors are presently visiting residential services, but the project is expanding to include providers of employment/training services such as developmental achievement centers and sheltered workshops. More volunteers are needed in Brainerd, Little Falls, Rochester, Crookston, and Anoka County where the project is to expand.

Partnership in Quality Services has produced a 24-minute videotape which is available on loan to service providers and special interest groups. Part I (8 minutes) includes an introduction to the project and an overview of quality of life issues and the monitoring process. Part II (16 minutes) simulates monitoring visits and describes the quality of life indicators in detail. For more information, contact: Jean Swanson, Project Director, at (612) 827-5641, or (800) 582-5256, toll free.

A STORY THAT I HEARD

The following selection is from **A Story That I Heard: A Compendium of Stories, Essays, and Poetry about People with Disabilities and American Life**, collected by David B. Schwartz, John McKnight, and Michael Kendrick, published by the Pennsylvania Developmental Disabilities Council, 1987:

BELCHERTOWN STATE SCHOOL

John Patrick, as told by Tryna Hope¹

I was eight years old. My mother said she couldn't take care of me. She had too many kids. The school didn't want me. They said I ran around too much. I learned to count by watching trains and making a mark with a stick on a piece of wood. Someone taught me those were numbers. My first day at Belchertown State School, when I was eight, they took me into a big room with many beds. Mine was by the window. I was happy about that because it was near a highway and I could see cars and count them. I was there until I was twenty-nine years old. Someone woke me up every morning. Then we got in lines--lines for showers, lines for eating, lines for everything. After the showers, the aides would beat us on our backs with hoses while we ran from the showers. I don't know why they did that. But I know it hurt. I ran away twice but they found me and brought me back. They put me in the "dog house," or seclusion, for a week for running away. I didn't know what I would do outside and I was really scared. But I know I wanted to get out.

¹ John Patrick shares an apartment with his roommate in Easthampton, Massachusetts. He is involved with a self-advocacy group and does volunteer office work at the Association for Retarded Citizens of Hampton County. Tryna Hope is a social worker who served as an advisor to the Open Door Club.

PUBLICATIONS

Getting the Job Done: A Manual for the Development of Supported Employment Programs for People with Physical and Multiple Disabilities, United Cerebral Palsy Association, October 1987. This manual was developed by the Program Services Department of the United Cerebral Palsy Association in response to affiliate priorities expressed in the Toward Excellence Survey. The manual represents a gathering of the best available information, theory, and practical guidance for developing supported competitive employment for people with cerebral palsy and other severe disabilities. The purposes of the manual are: 1) to provide an overview of the components and activities associated with the supported employment model; and 2) to present strategies for successfully responding to federal and state discretionary funding requests for supported employment demonstration projects. The manual contains a combination of administrative and direct service strategies for implementing supported employment programs. The eight sections in the manual represent a new way of thinking in employment philosophy: assessment, job development, job matching and placement, job site enabling, follow-along, and administrative considerations. The last section contains a number of resources and suggested forms. For further information, contact: United Cerebral Palsy Association, Inc.; 1522 K Street, Northwest; Washington, DC 20005. Tel. (800) USA-2UCP.

Adaptable Housing: A Technical Manual for Implementing Adaptable Dwelling Unit Specifications, U.S. Department of Housing and Urban Development, 1987. This publication offers a means for providing marketable accessible housing for everyone--an adaptable design approach that opens up the possibility for mass-produced, attractive, and universally usable housing in all sizes, price ranges, and locations. The authors point out that ever since provisions for accessible housing have been included in building codes and standards, the building industry as well as people with disabilities have been dissatisfied with most fixed accessible housing units mandated by state and federal laws. Among the complaints are inappropriate design details, inadequate space for families, clinical appearance, high vacancy rates, limited numbers, and poor locations. An adaptable housing unit is an accessible dwelling with adaptable features that eliminate the special appearance and/or meet the needs of the individual user by adding or adjusting elements. The adaptable design approach holds the promise of more universally usable housing in the future at little or no extra cost. This publication is available from: HUD USER; P.O. Box 280; Germantown, MD 20874.

How to Organize an Effective Parent/Advocacy Group and Move Bureaucracies: For Parents of Handicapped Children and Their Helpers, Charlotte Des Jardins, Coordinating Council for Handicapped Children, Chicago, 1980. Based on the experiences of the Coordinating Council for Handicapped Children in Chicago, this guide is intended to help parents to help themselves, and particularly, how to make waves in the

sea of bureaucratic stagnancy. A sample of chapter headings includes: do you get angry when; do parents make effective advocates; how to tell a bureaucrat from a public servant; uncovering buried talent; how to lobby and get results; and how to make headlines. The author states that caring is power. Sharing is power. Parents working together is power. Only you (the parent) can represent your son/daughter. To purchase this publication and others on similar topics, contact: Coordinating Council for Handicapped Children; 20 East Jackson Boulevard, Room 900; Chicago, IL 60604. Tel. (312) 939-3513.

CONFERENCES/WORKSHOPS

Project IMPACT: Understanding the Legal System is a one-day workshop that will be held in three different locations. The workshop is intended for nonlegal professionals with an interest in how child sexual abuse cases are handled within the criminal justice system. Workshops have been scheduled as follows:

March 9, 1988--Sheraton Northwest, Brooklyn Park
March 30, 1988--Best Western Motel, Mankato
April 13, 1988--Radisson Hotel, Duluth

For registration and more information, contact: Project IMPACT, Government Training Service, 202 Minnesota Building, 46 East 4th Street, St. Paul, MN 55101. Tel. (612) 223-5305, or (800) 247-1448 toll free.

April 20-22, 1988

MnDACA 88: The Next Generation is the theme of the Annual Conference of the Minnesota Developmental Achievement Center Association to be held at the Holiday Inn Downtown in Minneapolis. Presenters include: Jim Kern from San Antonio, Texas; Bruce Blaney from Boston, Massachusetts; Dee Everett, Lincoln, Nebraska (ARC/US); Ian Pumpian from San Diego, California; and Wade Hitzing from Columbus, Ohio. For more information, contact: MnDACA; 1821 University Avenue, S-270; St. Paul, MN 55104. Tel. (612) 647-9200.

April 27-29, 1988

Employment, Integration, and Community Competence: The Keys to Quality of Life and Community Coalescence, is the theme of this international conference sponsored by the Young Adult Institute to be held at the New York Hilton in New York City. The forum will bring together more than 250 prominent speakers to address over 2,500 professionals from around the nation and abroad. For more information, contact: Maureen Duffy; Young Adult Institute; 460 West 34 Street; New York, NY 10001-2382. Tel. (212) 563-7474.

LENDING LIBRARY SELECTIONS

The State Developmental Disabilities (DD) Program Office has acquired several education, training and resource materials. **The following materials may be borrowed from the State Office only, located at the address on the front sheet of the State Supplement section of this newsletter. Tel. (612)296-4018.**

Assessment of Individuals with Severe Handicaps: An Applied Behavior Approach to Life Skills Assessment, D. M. Browder, Paul H. Brookes Publishing Company, 1987. This comprehensive text covers the assessment of critical functions and life skills in persons with severe handicaps. Using applied behavior analysis, it examines the assessment of motor skills, communication, academics, and social behavior in the context of developing these skills across life domains. Five actual case histories (plus sample graphs, data sheets, and a flow chart) illustrate how to evaluate and respond to an individual student's performance on an ongoing basis. Helpful forms and evaluation sheets show how to match student preferences with environmental characteristics. Guidelines for writing task analyses help to promote instruction and generalization. Meaningful assessment is only one part of teaching, writes the author, but it influences every aspect.

Staff Development in Mental Retardation Services: A Practical Handbook, J. F. Gardner, and M. S. Chapman, Paul H. Brookes Publishing Company, 1985. This book is intended for students who plan to work in programs providing services to persons with mental retardation. It is also intended for new employees or staff of human service agencies who need to review basic information about service delivery to people with mental retardation. The chapters are designed as interactive learning and orientation packages. Learning exercises are assigned, for example, to observe a program; read an individualized program plan; or study agency policies and procedures. Chapters focus on such topics as: the principle of normalization, legal rights, assessment, interdisciplinary team process, developing instructional strategies, identifying and measuring behaviors, behavior management principles, maintaining safe environments, drugs, and medications, human sexuality, working with families, coping with stress and burnout, and management responsibilities.

**Metropolitan Council DD Program
300 Metro Square Building
7th and Robert Streets
St. Paul, MN 55101**

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DD Program, Metropolitan Council
300 Metro Square Bldg., St. Paul, MN 55101*

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SEE OPEN INVITATION - PAGE 5

DD

INFORMATION EXCHANGE

Published monthly by the Developmental Disabilities Program of the Metropolitan Council

Metropolitan Council
300 Metro Square Building
St. Paul, MN 55101
291-6427

Vol. 13, No. 14
April 1988

METROPOLITAN COUNCIL DD PROGRAM NEWS

The Metropolitan Council's FY 87 DD Case Management Project produced three aids that should help consumers, families, county case managers and other service providers understand more about case management for persons with developmental disabilities. The aids consist of a booklet, a videotape and an audiotape entitled: The Case Management Team: building Community Connections.

The videotape gives an overview of how quality case management can achieve genuine community integration. The audiotape is a series of interviews with three professionals who discuss with a parent what case management means and how it should work, how families can be active participants in major decisions about services and how they can participate in evaluating services to determine if they are actually beneficial.

Prior to the project, the only available written material on case management was Rule 185 which is the set of regulations to guide counties in their provision of case management services. There was no comprehensive information that families could use to better understand case management services. The Case Management Team: building Community Connections is written from the family viewpoint. It will be useful for case managers, other service providers and decision makers.

The booklet begins with an explanation of how and why attitudes and expectations about persons with severe handicaps have recently changed and how the service system is also changing. It calls the emerging concepts, the integration philosophy and defines the major principles that comprise the new philosophy. It explains the case management process, requirements of Rule 185, the case management team, and each team member's responsibilities throughout the process. It provides many suggestions for how to build community connections for persons with developmental disabilities through case management. It also includes illustrations and stories about people in Minnesota and other states for whom integration practices have worked and examples where traditional services have failed.

The last chapters in the publication discuss the difficulties encountered in changing from segregated and insulated services to an integrated system and how to prepare the community and generic services to appropriately adapt to meet the specific needs of persons with developmental disabilities.

Additional resources that readers can use are listed at the end of each chapter and in the appendices. The booklet also contains a variety of checklists (taken from a variety of nationally published materials) that will help readers determine whether services are of high quality and are promoting integration outcomes.

After April 15, 1988 the tapes and booklet will be available to readers in the seven-county Metro Area under the following conditions:

- The video tape and audiotape will be available on loan, free of charge. Organizations and individuals may make copies of both tapes to share with their members or other relatives.
- Up to 25 copies of the booklet are available to organizations upon request, free of charge. For larger numbers of copies, readers are asked to arrange to pick up their orders.

To order, call or write: The Metropolitan Council, Data and Information Center; 300 Metro Square Building; St. Paul, MN 55101; 291-6464.

For readers in Greater Minnesota or other parts of the country, the tapes and booklets are available free of charge from: The Governor's Planning Council on Developmental Disabilities; 300 Centennial Office Building; 658 Cedar Street; St. Paul, MN 55155; (612) 296-4018.

The case management project was funded jointly by the Metropolitan Council and the Minnesota Governor's Planning Council on Developmental Disabilities.

Activities, notices, services, products, etc. mentioned in this publication are for information purposes only and do not imply endorsement by the Developmental Disabilities Programs of the Metropolitan Council and the State Planning Agency.

FOR YOUR INFORMATION

Scholarship Offered

United Cerebral Palsy of Central Minnesota is offering a scholarship in the amount of \$500.00. Applicants for the 1988-89 academic year must be diagnosed as having cerebral palsy, and must be from Stearns, Benton, or Sherburne counties. Academic record, family resources, and availability of other aid will be considered. For further information contact: UCP of Central Minnesota, 1521 Northway Drive, St. Cloud, MN 56303 or (612) 253-0765.

Communicating with Legislators

To identify your state senator and representative you may wish to use this information: The State of Minnesota is divided into sixty-seven senate districts. Each senate district is further divided into two house districts making a total of one hundred thirty-four house districts. You may obtain the name and address of your state senator and representative by calling either the Senate Office (phone: 612/296-0504) or the House Office (612/296-2146).

First National Congress for Adults with Special Learning Needs

In fall, 1987 the First National Congress for Adults with Special Learning Needs was held. The Congress was convened to focus attention on the growing numbers of adults with disabilities who are seeking remedial, developmental, career, and leisure education in both public and private institutions. Lifelong learning for adults to enable them to become self-reliant and productive citizens was emphasized. Proceedings and a book with chapters written by the Congress facilitators are in press and a followup conference is planned for August, 1988. For details, contact the Congress co-chairs Boris E. Bogatz of Gallaudet University at (202) 651-5044 or William R. Langner of the U.S. Department of Education at (202) 732-2410.

Information for Dentists

A recently published article can assist dentists in better understanding the patient with developmental disabilities and their family's needs. Written by Sally Swallen, health education consultant for ARC Minnesota, the article is titled "Be Flexible and be Human: What the patients' families see when dentists treat people who are mentally handicapped." It was published in the Journal of the American Student Dental Association. ARC Minnesota suggests hand delivering the article to the family dentist or sending it by mail with a personal hand-written note. Copies of the free reprint may be obtained by calling ARC Minnesota (612) 827-5641 or toll free 1-800-582-5256

Sign Language used to Teach Hearing Children

In the Prince George's County, MD schools, teachers are using sign language when teaching reading skills to hearing children, especially when traditional methods have failed. Two neighboring counties have asked for training in the

technique because it has been such a success. In a University of Maryland study, instructors using traditional methods to teach reading comprehension and vocabulary retention found students retained 69% of the words. Using signed instruction the students retained 93% of the words. The sign instruction has been used in the county for about four years with primary school grades. Signing seems to give a visual quality to learning, thus making it easier to retain.

News Programs have Captioning

The early evening network news is now captioned on ABC, NBC, and CBS. The National Captioning Institute now captions over 28 hours of regularly scheduled news and public affairs programming a week. Consumers interested in knowing more about captioning and where NCI's Tele-Caption II decoder can be purchased may call NCI a 1-800-533-WORD (V/TDD)

RESOURCES/SERVICES

Computer Resource

"Apple Computer Resources in Special Education and Rehabilitation (1988) is a guide to Apple Computer's many rehabilitation and special education resources. edited and published by DLM Resources. DLM abstracted and annotated data from the computer and disability databases at Apple Computer; the Trace Research Center for Communication, Control, and Computer Access; and Closing the Gap to produce a clear, readily usable guide for consumers and educators. The book may be ordered by prepaying \$19.95 plus \$2.50 for postage and handling to DLM Teaching Resources, 1 DLM Park, Allen TX 75002.

AARM Meeting

More than 2500 attendees will participate in the 400 hours of offerings at the 1988 Annual Meeting of the American Association on Mental Retardation in Washington D.C. from May 29 to June 2, 1988. The conference offers special courses, debate groups, seminars, workshops, exhibits, poster sessions, film and video theater, and a banquet. A complete brochure with registration can be obtained by calling 1-800-424-3688 or writing AARM at 1719 Kalorama Road NW, Washington D.C. 20009

Resource on Autism

"Understanding People with Autism" is now available. Providing quality programs and services for individuals with severe behavior and communication disorders is a problem often faced by educators, residential and recreational service providers. A professional, video-based instructional package, providing a concise overview of the Autistic syndrome is now available for staff training. The straight forward approach of the materials is designed to develop and expand staff skills including behavioral observation and record keeping, planning for success, strategies for developing a communication system, principles of program planning in community settings. This instructional program was developed by Outcomes, Inc. and the Twin Cities Society for

Children and Adults with Autism (TCSAC) through a grant from the Minnesota State Planning Agency. The package includes two videos of real-life cases, and all callers will be guaranteed confidentiality. UHF will handle all complaints promptly, but will not provide emergency service. The service is an independent project of UHF, sponsored in part by Northwestern Bell.

Consumer Hotline Established

United Handicapped Federation (UHF) is offering a new service to Metro Mobility users, a 24-hour consumer hotline designed to handle complaints, suggestions and compliments about service. Metro users can call 649-3000 to discuss their situation with UHF. Data from the calls will be distributed to appropriate agencies, and all callers will be guaranteed confidentiality. UHF will handle all complaints promptly, but will not provide emergency service. The service is an independent project of UHF, sponsored in part by Northwestern Bell.

Resource in Locating Services

A new nonprofit company named Advantage Communications Inc. has been formed to provide a single resource to assist the public in locating services and products helpful to persons with disabilities. Advantage Communications' first product, scheduled for late this spring, will be a quarterly magazine. It will be distributed free-of-charge in the metropolitan area, and will feature stories by persons with disabilities, their families and professionals. For more information, call (612) 349-2747.

Conference for Professionals in the Field of Hearing Impairment

Chief Anthony Bouza, Minneapolis Police Department and Dr. Eldon Morey, Clinical Psychologist, Alexandria, Minnesota are the featured speakers at a conference for professionals in the field of hearing impairment sponsored by the Minnesota Chapter of The American Deafness and Rehabilitation Association. The conference will be held on April 22, 1988 at the Minnesota Landscape Arboretum, 3675 Arboretum Drive, Chanhassen, MN from 9:30 am to 3:30 pm. For further information call Deb Guthmann at (612) 624-4037 Voice/TDD.

Barrier Awareness Day

As part of its celebration of Barrier Awareness Day in Minnesota on May 6, the Minnesota Council on Disability plans to pursue a "bare-bones" accessibility survey of each of Minnesota's 87 county courthouses. Volunteers throughout the state are needed to complete the survey. The results will be shared at a press conference to be held at the State Capitol on May 6. To volunteer contact Leslee Lane at 296-6785 (Twin Cities), or 1-800-652-9747 (Greater Minnesota). Both numbers are voice and TDD.

New Program for Youth with Visual Impairments

The St. Paul Society for the Blind is offering a new program to help teenagers with visual impairments better understand the issues which are especially significant to adolescents. The Adolescent Support Project, currently being offered on a trial basis, was initiated to provide these teenagers with a forum to share their thoughts and discuss their concerns about issues that influence adolescent development. Such issues include dating, relationships, social situations, family life, adult responsibility and career planning. Teenagers between 14 and 19 years of age from the entire Twin Cities are eligible. For information, call (612) 224-7662

Metro Conference Set for Adults with Developmental Disability

"The Meaning of Independence," an all-day conference for adults with developmental delay or disability will be conducted Saturday, April 23, from 11:00 am to 10:00 pm at the Anoka Technical Institute, 1355 West Main in Anoka. Sponsored by the metro-area Associations for Retarded Citizens (ARCs), the conference will feature workshops about living independently, developing friendships, leisure-time options, self defense, AIDS, and quality of life. Sessions are also scheduled for accompanying staff and attendants. Cost for the event is \$10 and includes lunch, workshops and a dinner/dance. To obtain a registration brochure contact the ARC St. Paul at 224-3301, the ARC Hennepin at 874-6650, the ARC Anoka at 780-0560, or the ARC Suburban at 431-3700.

New Publication Describes How and Why Nonprofit Organizations get into Trouble

The Amherst H. Wilder Foundation recently published a report documenting a year-long project to discover how and why nonprofit organizations get into trouble, how they confront the issue of survival and how they gracefully go out of business. It is entitled "Nonprofit Decline and Dissolution Project Report" and is available from Management Support Services at a cost of \$5.00 per copy including shipping and handling. Prepayment is required to Wilder Foundation/MSS, Attn: Becky Andrews, 919 Lafond Ave., St. Paul, MN 55104.

Computer Resource for Persons with Visual Impairments

"The Second Beginner's Guide to Personal Computers for the Blind and Visually Impaired", 2nd edition from the National Braille Press (1987), updates the 1984 edition. The Guide reviews 18 products for the Apple, IBM/compatible, and Commodore computers and provides a final chapter of additional resource lists. Written by persons with visual impairments who are computer users, this book is a first hand guide to computing with speech or braille output and is a source of detailed consumer product reviews. Available in Braille, print or cassette for \$11.00 plus \$3.00 postage or shipping from National Braille Press, 88 St. Stephen Street, Boston, MA 02115.

Spring Conference of the Educator Network

The Minnesota Foundation for Better Hearing and speech is holding a conference centering around children with hearing impairments on Saturday, April 16 at the Sheraton Airport Inn in Bloomington, MN from 9:00 am to 3:45 pm. Topics will include assessment of preferred communication mode, psycho-social perspective of social emotional needs, task analysis of instructional objectives, and others. Keynoter will be Dr. Noel Matkin, Audiologist and Director of the Children's Clinic at the University of Arizona. Call Toni Johnson at the Foundation for registration information at (612) 223-5140 (V/TDD).

Beyond Baby M

"Beyond Baby M: Ethical Issues in New Reproductive Techniques" is the topic for a Continuing Medical Education session at the University of Minnesota on April 15, 1988. The workshop will address the many ramifications of the new reproductive technologies: medical, ethical, social and legal. It will include a diversity of perspectives drawing on those with expertise in history, philosophy, law, theology, public affairs, and medicine. Registration information can be obtained from Continuing Medical Education, U of M, Box 202, 420 Delaware Street SE, Minneapolis, MN 55455. The fee is \$75.

Quality of Life Conference

The American Association of University Affiliated Programs along with many other national organizations dealing with disabilities are cosponsoring on April 30 and May 1, 1988 a conference titled "Quality of Life for Persons with Disabilities: A Look at the Issues. It will take place at the Washington Hilton Hotel and Towers in Washington, D.C. For registration information contact the American Association of University Affiliated Programs, 8605 Cameron Street, Suite 406, Silver Spring, MN 20910

RECREATION/LEISURE

International Travel Opportunities

Mobility International USA (MIUSA) is a national non-profit organization whose purpose is to promote and facilitate inclusion of people with disabilities in regular international exchange and recreational travel experiences and development of alternative ventures for people with special needs. Those between the ages of 18 and 25, both with and without disabilities are invited to apply. This year's programs include: *Culture and the Arts in Germany in August (for those who have interests and skills in the creative arts and have completed one German class); *Disability Issues in China in September, 1988; and *Disability Issues in the USSR in summer 1988 (of special interest to persons with hearing impairments)

MIUSA offers travel information and referral service, news of international workcamp openings, and help with selecting and applying to international educational exchange organizations. It also provides internships to American as well as international students.

MIUSA has produced a new 20 minute educational video called "Looking Back, Looking Forward", which promotes the important role that persons with disabilities have in participating in international education exchange and travel programs. Persons who are quadriplegic, blind, have cerebral palsy, and those who are deaf, as well as non-disabled persons, discuss their experiences in England and Costa Rica. For details about travel programs or the video contact MUISA, P.O. Box 3551, Eugene, OR 97403.

Horseback Riding for Persons with Disabilities

Cloud 9 Therapeutic Horsemanship, Inc is offering horseback riding lessons for persons who have physical, mental, or emotional disabilities. The goals are to learn the skill of horseback riding, to ride as independently and safely as possible, and to improve physically in balance, coordination etc. Lessons are on Monday and Thursday evenings April through September. Call Trina Joyce at (612) 338-3961 for further information. Cloud 9 is located in Dakota County.

Summer Camping Opportunity

Camp New Hope offers a variety of summer camping programs. This year the summer camping program will include Exceptional Theater workshops where participants will create, rehearse, and perform an original play, a Very Special Arts workshop, an off-camp travel experience, and all the traditional camping activities. For further information contact: Nancy Benson, Camp New Hope, H.C.R. 3 Box 578, McGregor, MN 55760 or (218) 426-3560.

INFORMATION EXCHANGE

STATE
SUPPLEMENT

April 1988

Developmental Disabilities Program
100 Centennial Office Building
658 Cedar St.
St. Paul, Minnesota 55155

Minnesota State Planning Agency
Rogert Strand, *Editor*
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Member of
National Association of
Developmental Disabilities
Councils

GOVERNOR PERPICH APPOINTS NEW MEMBERS TO COUNCIL ON DEVELOPMENTAL DISABILITIES

Governor Rudy Perpich recently appointed the following people to serve on the Governor's Planning Council on Developmental Disabilities:

- Carolyn Elliott, of St. Paul, representing the Minnesota Department of Education;
- Virginia Marolt, of Gilbert, who will serve as a representative of parents of people who have mental retardation;
- Lorrie L. Ufkin, of Sherburn, representing parents of people with severe disabilities; and
- Carol Louise Werdin, of Minneapolis, representing the Minnesota University Affiliated Program on Developmental Disabilities;

The Minnesota Governor's Planning Council on Developmental Disabilities is a planning body composed of 27 members including persons with developmental disabilities and members of their families. The Council is charged with supervising the development of a three-year state plan describing the quality, extent, and scope of needed services being provided or to be provided to persons with developmental disabilities. The Council also assists in monitoring and evaluating the implementation of the state plan, and reviews state service plans for persons with developmental disabilities.

STUDY DOCUMENTS BARRIERS TO EFFECTIVE CASE MANAGEMENT: PAPERWORK, HEAVY CASE LOADS, AND TRAINING

A recent Minnesota study identified significant barriers to the provision of effective case management services for persons with developmental disabilities and their families. The amount of paperwork, heavy client caseload, inadequate training, staff shortages, insufficient funds, and the large number of required meetings were some of the common barriers identified in the study conducted by the Minnesota University Affiliated Program under a contract with the Governor's Planning Council on Developmental Disabilities, State Planning Agency. A summary report of the study is entitled: Policy Analysis Series No. 24: Minnesota Case Management Study/Executive Summary.

"With increased numbers of individuals with developmental disabilities being served in the community," the authors stated, "the coordination of appropriate services becomes an important immediate concern." Case management is often described as the process of coordinating assistance to individuals with special needs which includes advocacy, monitoring, administration, and service coordination.

In Minnesota, the Department of Human Services has promulgated Rule 185 (Parts 9525.0015 to 9525.01565) which establishes the procedures that the Minnesota counties will follow and will be responsible for in the provision of case management services to all persons with mental retardation and related conditions. The overall purpose is to "ensure that each person with mental retardation or a related condition who applies for services (or whose legal representative applies for services) receives a diagnosis and assessment of current condition, and that, based on the information gathered, services are designed, arranged, provided, and monitored so that the services meet the level of the person's need in the least restrictive environment and in a cost-effective manner" (Part 9525.0025, subpart 2, line 4).

In 1986, the Governor's Planning Council on Developmental Disabilities established case management services as a priority consideration in its Three-Year State Plan. Subsequently, a grant was awarded to the Minnesota University Affiliated Program (MUAP) to assess the extent and nature of the problems. The MUAP conducted a survey of county case managers, case manager supervisors, and county directors of human services agencies. The questionnaires gathered information on different aspects of case management, including training, case manager to client ratios, caseload compositions, barriers to effective case management services, and percentages of time spent on case management functions. Altogether, out of 497 questionnaires mailed, 332 were returned, resulting in an average response rate of 67 percent.

Highlights of the survey findings are as follows:

Academic and In-service Training:

- The majority of case manager supervisors and case managers held a bachelor's degree, and the most common educational major was social work.

- Nearly all of the 37 supervisors who responded to the survey indicated that they had no courses in case management prior to or after their employment as supervisors.
- Eighty percent of the 195 case managers responding to the survey indicated that they had no formal coursework in case management.
- Sixty-one percent of the supervisors indicated that they had taken no coursework in the field of developmental disabilities prior to becoming a supervisor. Most (97 percent) indicated that they had not taken a course in developmental disabilities since becoming a supervisor.
- Among case managers, 55 percent of the respondents reported taking no coursework in developmental disabilities and 23 percent had taken only one or two courses in the area.
- Regarding in-service training, most of the supervisors (84 percent) and case managers (88 percent) had received in-service training in both case management and in developmental disabilities between 1981 and 1987.

Staffing Patterns:

- As expected, the larger counties employed the largest number of supervisors. Of the 60 county directors responding, representing 62 counties, 13 percent had no supervisors, 23 percent employed only a part-time supervisor, and 52 percent employed one full-time supervisor.
- Over half of the counties employed between 1 and 2 case managers, with four of the large counties employing between 26 and 44 case managers.
- The majority (60 percent) of the case managers had no case aide assisting them, while 25 percent received from 1 percent to 25 percent of the case management aide's time.

Clientele and Case Manager-Client Ratios:

- Of the 192 case managers, it was reported that 4.4 of their client population with developmental disabilities were children from birth to 5 years; 12.5 percent were between the ages of 6 and 21 years; and 83.0 percent of their clients were adults.
- Fifty-five percent of the case managers had a combination of clients with and without developmental disabilities. The average proportion was 81.2% with developmental disabilities and 18.8% without.
- The average caseload of clients with and without developmental disabilities was over 68 persons, a ratio twice that used by other states as a standard for effective case management.

- Among supervisors, 17 percent reported carrying a caseload which ranged from 1 client to 95, with a mean of 37 clients.

Barriers To Effective Service:

- The most notable barriers considered by the case manager supervisors were: (a) the amount of paperwork, (b) the heavy caseload size, (c) staff shortages, and (d) lack of day program options for clients.
- The majority of case managers identified the following barriers: (a) too much paperwork, (b) staff shortages, and (c) insufficient funds to accomplish the job.

Training Needs:

- The most commonly cited training needs by supervisors was learning how to monitor the quality of services to individual clients. Other areas included: (a) assisting clients and families to become their own service coordinators, and (b) learning methods for negotiating with clients and service providers when the client disagrees with individual service plan components.
- Case managers identified the following areas: (a) methods for negotiating with clients and service providers when there is a disagreement; (b) how to develop an individual habilitation plan; (c) methods for procuring accurate information related to service options; and (d) how to assist clients in becoming their own case managers.
- The item least frequently marked was information on history, normalization, and values.

Recommendations:

- County directors recommended almost unanimously that the State of Minnesota apply for Medical Assistance Funding under the Consolidated Omnibus Reconciliation Act to gain more funding for case management services.
- There are currently 290 case managers serving an estimated 15,000 persons with developmental disabilities in Minnesota. To meet a 1:30 caseload ratio, an additional 210 case managers would be needed with an additional \$7,350,000 to be added to the existing budget for the Department of Human Services.
- Regarding the amount of paperwork, the Data Integration Projects of Dakota and Itasca Counties, innovative projects funded by the Governor's Planning Council on Developmental Disabilities, a computer-assisted program to reduce paperwork required of human services personnel, appears to hold promise for decreasing time spent on paperwork and increasing time devoted to clients and their needs.

- The Department of Human Services, Division for Persons with Developmental Disabilities, counties, and universities should implement a cooperative effort toward improving preservice training programs to eliminate the necessity of case managers receiving a fragmented education after employment.
- In-service training for case managers should be better coordinated so that workshops will be offered on a consistent basis and, over time, will present comprehensive philosophy, information, and skills development for case managers in the field.

Copies of the Executive Summary will be automatically sent to those on the Policy Analysis Series mailing list. Others may request a copy from: Governor's Planning Council on Developmental Disabilities; 300 Centennial Office Building; 658 Cedar Street; St. Paul, MN 55155. Tel. (612) 296-4018.

A STORY THAT I HEARD

The following selection is from A Story That I Heard: A Compendium of Stories, Essays, and Poetry about People with Disabilities and American Life, collected by David B. Schwartz, John McKnight, and Michael Kendrick, published by the Pennsylvania Developmental Disabilities Council, 1987:

EDUCATING TOMPKINS PARK: MICHAEL AT THREE Duncan Whiteside¹

Trees greenly screened the slide. Kids shouted, "Hey, mister, watch this," plummeting down head first, a solution to the riddle of the falling tree within the forest, soundless without ears to hear it.

Michael, patient, trailed warmly on my hand. Yards away, mothers chattered by their kids, bunched on benches, brown and white, Spanish and Ukranian, floating with the sounds where big kids danced behind the bushes.

A hush fell like forest danger, when we brushed too close. Mothers, like our forebears on the prairie, made a safe, tight circle for defense. "Look at that, how'd he get that way? Mine's o.k., thank God." (Must we teach them all? Would life be long enough for that?)

Then, "Hey mister, what's wrong with him? He ugly, he eye broken." The boy was Michael's size.

"He got sick before he was born," I say, thankful someone wants to know.

"Oh," he said. "Look at me," running to the slide.

¹Duncan Whiteside, who lives in Port Washington, New York, is the father of three children. Michael, second oldest, is now twenty-two.

WANTED: A STORY THAT YOU HAVE HEARD OR EXPERIENCED

The Governor's Planning Council on Developmental Disabilities would like to publish a series of articles in this newsletter and perhaps even assemble a book similar to the one published in Pennsylvania called A Story That I Heard. (See above article.) Here is an opportunity for frustrated writers or story tellers of Minnesota to share their experiences and thoughts. If you have a story that shares something about the beauty within another person, if it breaks new ground toward understanding one another, if it brings out the joys, sorrows, or rare moments of ecstasy and helps others to achieve a new way of thinking about people with disabilities, then it is very likely a story that needs to be heard a thousand times. You do not have to be a polished journalist or writer to relate an experience that you or someone close to you once had. Most likely with a little editing, your story can be published. Full credit will be given to the author if your story is selected. Anonymity and confidentiality will also be respected. Please send your story to: Editor; DD Information Exchange--State Supplement; Governor's Planning Council on Developmental Disabilities; 300 Centennial Building; 658 Cedar Street; St. Paul, MN 55155. Tel. (612) 296-4018.

PUBLICATION ^{*}

Quality Health Care for People with Developmental Disabilities: A Guide for Parents and Other Caregivers, K. M. Pfaffinger & R. P. Nelson, Minnesota University Affiliated Program on Developmental Disabilities, 1988. These guidelines were prepared through a contract with the Developmental Disabilities Program of the Minnesota State Planning Agency with funds provided by the Governor's Planning Council on Developmental Disabilities. Based on the premise that all people have a right to quality health care, this guide emphasizes that assisting people with developmental disabilities to obtain health care and maintain healthy life styles will enhance the quality of their lives at home and in the community.

The major sections of this publication include: 1) being a more effective consumer advocate in selecting and working with health care providers; 2) managing routine health care, and developing healthy lifestyles; 3) managing common illnesses and more complex problems that affect the lives of individuals with developmental disabilities; and 4) finding resource materials and organizations of potential help in obtaining appropriate health care. To obtain a copy, contact: Minnesota University Affiliated Program on Developmental Disabilities; University of Minnesota; 6 Pattee Hall; 150 Pillsbury Drive, Southeast; Minneapolis, MN 55455. Tel. (612) 624-4848.

INTEGRATION VIDEO AVAILABLE: REGULAR LIVES

The Association for Persons with Severe Handicaps (TASH) recently announced that a new videotape has been approved for national airing by the Public Broadcasting Sys-

tem and is ready for distribution. The video called, Regular Lives, was funded by the U.S. Department of Education, the New York State Developmental Disabilities Planning Council, TASH, and other state, local and national organizations.

The 28-minute documentary, which focuses on people with developmental disabilities in typical school, recreational, and work settings, is an affirmation that integration works and is good for everyone. The three primary goals of the video are: to promote public education about the concept of integration; to train staff on the concept of integration; and to reach and educate parents, agencies, and community citizens on integration.

Cost: \$30.00, plus \$4.50 shipping and handling. Send check or money order, or call in your Visa or Mastercharge number to: WETA; Educational Activities; Box 2626; Washington, DC 20013. Tel. (800) 445-1964.

LENDING LIBRARY SELECTIONS

AIDS: Teaching Persons with Disabilities to Better Protect Themselves, Young Adult Institute, New York, 1987. This is a videotape (VHS) and Training Manual which was developed because all people are at risk of contracting AIDS, Acquired Immune Deficiency Syndrome, even people with disabilities. The material shown in the tape is presented in a concrete way to enhance learning by persons with developmental disabilities how to better protect themselves from this deadly disease. Sexually explicit scenes are shown. Professional discretion is advised.

Metropolitan Council DD Program
300 Metro Square Building
7th and Robert Streets
St. Paul, MN 55101

*If you no longer wish to receive this newsletter,
please call (612)291-6364, or write to the
DD Program, Metropolitan Council
300 Metro Square Bldg., St. Paul, MN 55101*

(TIME-DATED MATERIAL)

Community-Based Living Options for Young Adults with Deaf-Blindness: Philosophy, Directions, and Strategies, S. S. Barrett, T. S. Carr, & A. M. Covert (Eds.), Helen Keller National Center, 1987. "To be in the community is to live in the community and have access to all the community has to offer," state the editors of this book. This publication promotes choices and options for support systems which allow young adults with deaf-blindness the freedom to live where and with whom they choose with only the necessary amount and type of assistance they require. It addresses "bricks and mortar" issues as well as program issues. It is meant to be a primer on the wide range of issues these programs face in their attempt to promote and provide community living options in integrated settings.

Resource Guide for Working with Deaf-Blind Persons, Functional Independence Training, Inc., Minneapolis, 1987. This publication was developed out of the need for a compilation of general information regarding service provision for people who have both vision and hearing loss. It provides basic resources which can be used as the starting point for those wanting to access service providers for individuals with deaf-blindness in their particular geographical region. It also provides the reader with a brief overview of certain aspects of deaf-blindness including specialized needs and services, adaptive equipment, and terminology.

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METROPOLITAN COUNCIL DD PROGRAM NEWS 1988 AGENDA: REALIZING THE VISION

"....all of the community cried"

Leo died on the evening of August 25, 1987, and all of the community cried. Leo was a special man of 68 years. He stood six feet tall with brown hair which was greying, green eyes, and a protruding lower lip. Leo was a friendly person who talked to anyone who passed by. He was very outgoing and made you feel special when you talked with him. Leo always had candy available to share with his friends.

In addition, Leo was a person who had developmental disabilities, including epilepsy. As a result of his seizures he required a wheelchair. He had lived 30 years of his life in institutions which cared for people with mental retardation. The last 10 months of his life he lived in a foster home, where he received home and community-based waived services. It was during this last ten months of his life that Leo truly became a member of his community and family. Living with foster parents and their six grade-school children in a small community in central Minnesota during 1987, Leo's special needs were met by professional staff coming into the foster home. In addition, Leo worked at a developmental achievement center.

Leo loved his new family and he enjoyed being a part of a community. He attended church every Sunday with his new family, using the ramp that the church had installed for people in wheelchairs. Leo's attachment to the community was evidenced by his interest in a Centennial celebration that occurred there this past summer. He was an avid Twins fan and enjoyed discussing these games with his neighbors, friends and his priest. Leo's placement in a foster home allowed him to visit with relatives of his foster parents, and his new neighbors. He was able to enjoy a quality of life he had never had during the past 30 years. His last birthday was a special one for him because his foster parents brought him to St. Cloud where he went out for dinner with his childhood friend.

Leo's quality of life was reflected at his funeral mass, which was attended by many of his friends from the local DAC, his sisters, and several nieces. His new family also was in attendance. His foster parents attended with two of their children who lived at home, six of their adult children, two in-laws, and four grandchildren. During the homily, Leo's priest talked about Leo sitting in the church in his wheelchair where he would wait until everyone had left the church so that he and the priest could discuss his work, the Twins baseball team, and his busy schedule at home. During the offertory, a staff member presented baseball magazines, three friends from the DAC presented candy, and two of the foster parents' children bought wine and the host to the altar. Leo's foster mother sang his favorite hymn.

The women of Leo's church served a meal following the funeral mass. While his friends talked about how much they were going to miss him, his sisters expressed joy that he had lived with a family that cared so much about him. His foster family knew that there would be a void in their lives, and were thankful that Leo had lived with them. He added so much to their family life.

All of these things are a true reflection of the quality of life that Leo enjoyed during 1987 when he became a part of the community by moving into a waived service foster home. He was loved, not only by the people paid to care for him, but by their families, his neighbors, his co-workers, and community leaders. Leo gave and Leo received from his community during the last 10 months of his life. He was a precious man, and we dedicate this article in remembrance of him, with the hope that all people with developmental disabilities who are living in institutions can someday come home to their communities.

*By, Pat Atwood, Casemanager
Stearns County Social Services*

Leo was fortunate to be a part of the Stearns County thrust into Community Empowerment and was one of 49 other individuals in foster home waived services in that

Activities, notices, services, products, etc. mentioned in this publication are for information purposes only and do not imply endorsement by the Development Disabilities Programs of the Metropolitan

county. According to Tim Jeffreys, Supervisor in Stearns County, the County Commissioners decided to move away from shift staff services to truly home-like settings. The Community Empowerment vision sees people with developmental disabilities making their own decisions and being able to carry them out, sees efforts made to help the person become a part of the community, and seeks to empower individuals to take more control over their lives and to have foster families assist in making this possible. Leo had become a part of his community by making all kinds of networks in the community with people who were not paid to be with him. His foster family provided assistance in making natural connections with neighbors, relatives, the priest, co-workers and many others. Leo had become empowered if only for a short time. Way to go Stearns County You are making the vision a reality.

agencies. The findings provide an overview of the nature of services available to children and adolescents with developmental disabilities, and their families who are receiving child welfare services. Forty-eight states were represented in the preliminary results.

A study underway in a midwestern state suggests that 40% of all children in the child welfare service system have developmental disabilities. Children who are mentally retarded and/or whose parents have mental retardation are increasingly becoming involved with Children's Protective Services nationwide as a result of physical neglect. For more information, contact: NRIC, Child Development and Mental Retardation Center, University of Washington, Mail Stop WJ-10, Seattle, WA 98185.

Public Hearing on Barriers in Employment to be Held

The Minnesota State Council on Disability and the Consumer Advisory Council, Division of Rehabilitation Services, Department of Jobs and Training in cooperation with the Governor's Initiative on Technology for People with Disabilities are holding a series of public hearings in the state. Public testimony will be heard at three different sites and panelists will consist of legislators, hearing sponsors, and members of labor.

May 19 - St. Paul-Martin Luther King Center
270 North Kent, 10:00 a.m. - 2:00 p.m.

May 31 - Albert Lea-Freeborn County Courthouse
411 South Broadway, 6:00 p.m. - 9:00 p.m.

June 2 - Moorhead-City Hall, Senior Citizens Room,
Basement 500 Center Avenue, 6:00 p.m. - 9:00 p.m.

Employers may submit written testimony but oral testimony will be heard from persons with disabilities only at this time. Testimony should relate to personal experiences in discrimination based on physical, program, bureaucratic or attitudinal barriers, promotional barriers, governmental disincentives, possible solutions or successes. To register to testify call Carol Kendall at the Minnesota State Council on Disability at 296-6785 or 1-800-652-9747.

VOLUNTEERS NEEDED

50 Parents and Casemanagers for people with developmental disabilities are needed to review and evaluate a new videotape and audiotape on Casemanagement produced by Metropolitan Council's Developmental Disabilities Program. The tapes were produced as a part of a grant project in 1987 funded by the Governor's Planning Council on Developmental Disabilities.

**Thursday, May 26, 1988
10:00 to 11:00 a.m.**

**Wilder Foundation Administration Building
Auditorium, Lower Level
919 Lafond
St. Paul, Minnesota**

Directions: Take interstate 94 to the Lexington exit in St. Paul. Go north six blocks to Lafond. Go east on Lafond. Turn left to enter the parking lot at the top of the hill.

A copy of the Metropolitan Council's companion booklet The Case Management Team: Building Community Connections will be given to each volunteer at the end of the session.

**For more information contact: Kay Zwernik at
291-6364.**

FOR YOUR INFORMATION

Editors note: Metropolitan Council is in the process of changing from a laser printing system for the DD Information Exchange to a desk top publishing system which was used in the April issue. For a while each issue may look slightly different as we are experimenting with different font styles, margins, headings etc. Please bear with us while we go through this transition.

Disability in Child Welfare System

The National Resource Institute on Children and Youth with Handicaps (NRICH), project of The Child Development and Mental Retardation Center in Seattle, has conducted a national study on "The Status of Children with Developmental Disabilities in Child Welfare Services." The surveyors conducted telephone interviews

An Evening of Unforgettable Theatre

Two performances of IMAGES, a play created by the Living Stage Theatre of Washington, D.C. will be presented in the Twin Cities in May. IMAGES is a provocative play about the hopes and struggles of a teenager who has a disability. While trying to realize his dreams, he confronts the pressures and the prejudices of the nondisabled world. The play will be presented free of charge on Saturday, May 14th and Sunday, May 15th at 7:00 p.m. The performances will take place in the theater of the Janet Wallace Fine Arts Center at Macalester College, 1600 Grand Avenue, St. Paul, MN. Reservations are on a first-come, first-served basis at 696-6359.

Proposals for New ILC requested by DRS

The Division of Rehabilitation Services (DRS) is accepting

proposals to establish a Center for Independent Living in an area of Minnesota presently not being served by a center. Approximately \$75,000 in state funds will be made available July 1st for the establishment of the new center. Centers for Independent Living are private, nonprofit organizations governed by a board of directors, a majority of whose members have disabilities. In addition, 50 percent of the center's staff must be persons with disabilities. Communities needing additional information can contact Scott Rostron, director, Independent Living Program, 612/ 296-5085.

SERVICES

Scouting Programs for Children

The Boy Scouts of America, Indianhead Council welcomes children with disabilities to its programs. Any boy between the ages of 6 and 21 years and any girl 14 to 21 is eligible for participation in Scouting. Scouting challenges and strengthens young people in their physical, psychological, social, spiritual, and vocational life. Scouting also provides appropriate opportunities for growth, success, and increased self-esteem. Boys in the Cub or Boy Scouts meet weekly in small groups under the direction of adult volunteers for recreational activities or to work on a challenging advancement program. The Exploring program for adolescents brings young men and women together to explore career and hobby interests. Children with mental retardation can participate in integrated Scout units or in special units.

Parents choose which setting would be best for their child. For more information call: Tom Frantzen at 612/224-1891.

NEW RESOURCES

ARC Minnesota Produces Videotape

Included as a part of their casemanagement grant funded by the Governor's Planning Council on Developmental Disabilities, ARC Minnesota has produced a videotape "Partnership for Quality Services". The target audience is primarily volunteers and consumers, but others interested in knowing more about the project would find it interesting. The first part of the 24 minute production gives an overview of the project on the volunteer monitoring process by focusing on quality of life indicators. The second part looks in detail at each quality of life indicator, shows scenes relating to various aspects of the indicator, and asks questions about what the viewer is seeing. Service providers can use the video as a springboard for discussion with staff. The video may be purchased for \$16.00 from ARC Minnesota, 3225 Lyndale Ave. So., Minneapolis, MN 55408. The video may be loaned from ARC Minnesota 612/827-5641 or the Governor's Planning Council on Developmental Disabilities 612/296-4018.

PUBLICATIONS

Autism Research Review International is a quarterly publication of the Institute for Child Behavioral Research. It contains up-to-date news on biomedical and educational research in the field of autism and related disorders. Some recent topics have included "social deficits", vitamin treatments such as B6 and folic acid,

in Japan. To order: Send \$15.00 for a one-year subscription to Autism Research Review International, Institute for Child Behavior Research, 4182 Adams Avenue, San Diego, CA 92116.

The U.S. Department of Education unveiled a new handbook which outlines the rights of persons with disabilities under a civil rights law. The 14-page pamphlet, "Handicapped Persons' Rights Under Federal Law," spells out the rights of persons with handicaps under Section 504 of the Rehabilitation Act of 1973. It includes the addresses and telephone numbers of ten regional civil rights offices where people can file discrimination complaints. It explains the responsibility schools, colleges, and other recipients of federal aid have to make their programs accessible to persons with handicaps. It also explains the protections persons with handicaps have on the job and in health, welfare, and social programs. To order a free copy of the handbook in English or Spanish write: Fred Tate, Office for Civil Rights, U.S. Department of Education, 330 C Street SW, Washington, D.C. 20202.

Children with Epilepsy: A Parent's Guide was compiled and edited by a mother whose three-year-old son has infantile spasms. The book is designed to educate parents and show what they can do to create a brighter future for their children. Chapters are written by some of the country's foremost authorities on epilepsy, and cover such topics a "What is epilepsy?" "Your Child's EEG," "Helping your child develop self-esteem," "An introduction to special education," "When epilepsy is not the only problem," and "Legal rights and hurdles." Two chapters are also written by Helen Reisner who is the editor of the book. To order send \$12.95 to: Epilepsy Foundation of America, 4351 Garden City Drive, Landover, MD 20785.

"PALAESTRA" is a quarterly magazine publication on "The Forum of Sport, Physical Education and Recreation for the Disabled" and is published in cooperation with the United States Olympic Committee's Committee on Sports for the Disabled. Each issue focuses on feature articles about all types of sports and recreational activities accessed by all age groups and covering all disability groups. A one-year subscription is \$18.00 for four issues. For further information contact: PALAESTRA, Challenge Publications, Ltd., P.O. Box 508, Macomb, IL 61455. 309/833-1902.

"Implementation Strategies for Improving the Use of Communication Aids in Schools Serving Handicapped Children" is a newly published series of five booklets offered by the ARC-USA. Eleven model outreach sites in the country were chosen and their programs analyzed to determine why they have been successful and how they overcame obstacles in developing communication services for children. The booklets are written for school administrators, educators, medical personnel, consumers and the general public and can be used for information sharing, advocacy, and considering various service delivery models, funding sources and staff training approaches.

WORKSHOPS/CONFERENCES

May 6, 1988

Empowering Ourselves: Self Defense for People with Disabilities, a day-long conference covering the many aspects of self-defense that can be used by people with disabilities. The conference will be held at the Holiday Inn Town Square, 411 Minnesota, St. Paul, MN. The fee is \$25.00 and includes lunch. The Minnesota Coalition for battered women and the United Handicapped Federation are the sponsors of the event. Register by May 2nd to Kathy Schumacher, MCBW, 570 Asbury St., Suite 201, St. Paul, MN 55104.

May 12, 1988

Building Integrated School Communities is a workshop sponsored by the Minnesota Association for Persons with Severe Handicaps, the Minnesota University Affiliated Program at the University of Minnesota, and the Metro Area Strategic Planning for Low Incidence Services in Education. It will address the rationale for integration; regular education integration; how integration is an integral part of future and community referenced curriculum; accommodations and adaptations for teachers; ways to promote friendships; and ways to build a base of support for change at the school building level. There is a \$5.00 charge which includes a snack, dinner, and materials. The presenters will be Drs. Terri Vandercook and Jennifer York. Send registration fee to: Metro ECSU, 3602 Highcrest Road N.E., Minneapolis, MN 55418 by May 5th.

May 18, 1988

Peer Support: For All Ages is a one-day workshop presented by Dr. Barbara Varenforst, a consulting psychologist from California who is co-founder of the Peer Counselor Training Program used in schools throughout the country. The workshop will include a focus on the value of peer support, development and maintenance of peer support programs and ways professionals and volunteers can work together. The fee is \$35.00 and includes lunch and materials. The location is the Sheraton Midway, 400 North Hamline, St. Paul, MN. Send registration to: Wilder Foundation, Community Care Resources, 919 Lafond Avenue, St. Paul, MN 55104. 612/642-4060.

May 17,24,31, 1988

Assertiveness Training is a three-part workshop presented at Courage Center for parents who have a child with a disability. The focus will be on teaching assertiveness and communication skills whether in person, by phone, or in writing in a physician's office, at a school IEP conference or at a social service agency. The registration fee is \$5.00, adjusted fee available. Call Annette Pantel to register at 612/520/0438. Courage Center is located at 3915 Golden Valley Road, Golden Valley, MN.

May 9 and 16, 1988

Another workshop at Courage Center is a two-part series on **Cognitive Delays and Mental Retardation**. Jim Kodadek, ARC Hennepin, will lead the series which will focus on definitions, terms, and tests plus coping with

mental retardation as a family. The workshop is geared for parents with children under six years of age. The time is 7:00 to 9:00 p.m. Call Kris Livingston at 612/520-0460 to register. Grandparents, older siblings, and relatives are welcome.

June 2-4, 1988, San Francisco

June 16-18, 1988, Washington, D.C.

Innovative Employment Programs for People with Disabilities: How to Get the Money will assist program managers and project directors to think more innovatively about designing high-impact programs, preparing proposals in more creative ways, raising funds for new ideas in new ways, using computers in employment programs, and trying spin-off businesses. The registration fee is \$300. Contact: Berkeley Planning Associates, 3200 Adeline Street, Berkeley, CA 94703 for more information or call 415/652-0999 Ext. 227.

June 20-24, 1988

The Grantsmanship Center of Los Angeles, CA has announced its schedule of training programs for the rest of 1988. The first one scheduled for the Twin Cities is the **Grantsmanship Training Program** which is a comprehensive 5-day workshop covering foundation, corporate and government funding and the preparation of grant proposals. This course is for beginners as well as more experienced persons and considers all aspects of researching for grants, writing grant proposals, and negotiating with funding sources. Tuition is \$495. For registration information contact: The Grantsmanship Center, 650 So. Spring Street, Suite 507, P.O. Box 6210, Los Angeles, CA 90014. 800/421-9512. The workshop will be conducted at the Robbinsdale Community Education Center.

Three workshops presented by the Minnesota University Affiliated Program and the Minnesota Association for Persons with Severe Handicaps

May 5, 1988

Issues and Dilemmas in Community Services with Jerry Provencal, Director of the Macomb-Oakland Regional Center, Mt. Clemens, Michigan.

May 12, 1988

Family and Client Perspectives on Disability with Ed Roberts, President of the World Institute on Disability, Berkeley, California.

May 26, 1988

On the Leading Edge: Progressive Practices in the Field of Developmental Disabilities Use of technology, adaptive equipment, and non-aversive techniques in integrating persons with multiple handicaps into the community. The presenter is Karen Green McGowan, Consultant in Health and Developmental Disabilities, KMG Corporation, Atlanta, Georgia.

All workshops are at the Earle Brown Continuing Education Center on the St. Paul campus of the University of Minnesota from 4:15 to 7:00 p.m. There is a fee of \$10.00 for each workshop for community participants. A wine and cheese reception will follow the first two workshops.

INFORMATION EXCHANGE

STATE
SUPPLEMENT

May 1988

Developmental Disabilities Program
300 Centennial Office Building
658 Cedar St.
St. Paul, Minnesota 55155

Minnesota State Planning Agency
Roger Strand, *Editor*
612/296-4018

Member of
National Association of
Developmental Disabilities
Councils

NEWS MEDIA NOT COVERING REAL DISABILITY ISSUES, JOHNSON CHALLENGES

"The news media is the most powerful arbiter of public opinion today, and it is the media that perpetuates inappropriate attitudes about people with disabilities." These comments were made by Mary Johnson, editor of The Disability Rag magazine on April 20, 1988, in her presentation on "Media and Change" during "disABILITY Awareness Days" at the University of Minnesota-Minneapolis Campus.

"Disability is one of the most important issues today—particularly for people who do not have a disability, she stated." "It is my observation," she continued, "that people who do not have a disability spend a considerable amount of time and energy trying to keep people with disabilities separate and out-of-sight."

For example, she pointed out, in the book And the Band Played On, it was observed that AIDS (Acquired Immune Deficiency Syndrome) was kept from being recognized by the media as a major issue since "it didn't affect 'real' people." "Once realized that AIDS could affect the entire population, it is now a trend, almost to a fault," she added. "We must realize that changes in society are occurring constantly and that only then does the media pick up on such changes. Real understanding by the public about such changes is dependent upon adequate handling by the media."

"For example," she continued, "the usual level of understanding about people with disabilities by the general public is, 'Oh, yes, isn't it lovely that we're putting in all these ramps!' The public is not informed about the real issues, such as, there has not been one article written about the fact that people with disabilities are the poorest, have the highest rate of unemployment, and live in the least adequate the unsafest housing situations. "Yes, maybe things are better, but maybe from unconscionable to deplorable!" Johnson stated.

"The usual coverage in the media about people with disabilities is under the category of 'the overcomers.'" This is Johnson's term for the barrage of stories about people with handicaps that are usually intended to inspire pity, or to exemplify the courageous and awe-inspiring. "What happen is that people with a disability serve as convenient symbols for selling newspapers. Because

reporters see people with handicaps as symbols, they don't know how to handle people with handicaps as real people," she challenged.

"One myth held among media reporters about people with disabilities is that, 'They're such a small group.'" "Wrong!" said Johnson, "the population with disabilities happens to be the largest minority group in the country—most of whom can read, watch television, and vote," she added.

"It was the attitude of, 'It's too narrow a topic,' response by a major editor with U.S. News and World Report that caused their news reporter, Joe Shapiro, to get his coverage of the Gallaudet student protest printed by The Washington Post," Johnson observed. "Shapiro had been told by his editor that, 'We've already covered that issue!'"

What should people with disabilities and their advocates do? Johnson said, "Since the news media thrives on breaking news and controversy, we have to create a scene to get their attention and to focus on the real issues. Also, write letters to the editors. The media is very vulnerable to criticism. Be specific and have something newsworthy," were her concluding suggestions.

The Disability Rag, with its irreverent, unapologetic point of view, has become one of the country's leading publications covering disability rights issues. Subscription information may be requested by writing: Subscriptions; The Disability Rag; P.O. Box 6453 Syracuse, New York 13217.

PUBLIC/CONSUMER PARTICIPATION REQUESTED PREPARATION OF 3-YEAR STATE PLAN ON DEVELOPMENTAL DISABILITIES

The Minnesota Governor's Planning Council on Developmental Disabilities is launching two major activities this spring and summer that will gather the necessary information needed to assemble its next Three-Year State Plan and a special 1990 report to Congress. The two activities include: 1) a sample survey of consumers, and 2) a series of public forums that will be scheduled throughout the state.

First, volunteers are requested to participate in a survey that will help the Council: 1) to measure and document the level of consumer satisfaction with services; 2) to establish priorities for the Council's Three-Year Plan; and

3) to meet other federal requirements for submission of the 1990 Report to Congress. The 1990 Report will document the populations with physical and/or mental impairments who are underserved or not being served. People interested in participating in this survey should complete the form provided in the centerfold of this newsletter indicating their willingness to participate.

Second, a series of Public Forums will be held throughout the state during the last three weeks of July 1988. People are encouraged to provide testimony that will help to direct the Council's selection of priority activities for its Three-Year State Plan. These public meetings are tentatively being planned to take place in the following locations:

Albert Lea	International Falls
Bemidji	Montevideo
Brainerd	New Ulm
Crookston	St. Cloud
Duluth	St. Paul
Fergus Falls	Virginia
Grand Marais	Winona
Grand Rapids	Worthington

The exact times, dates, and locations will be announced in the June issue of DD Information Exchange--State Supplement.

The new Developmental Disabilities Assistance and Bill of Rights Act of 1987 (Public Law 100-146) (see DD Information Exchange--State Supplement, December, 1987, page 5), mandated a national initiative to obtain consumer input to the planning process:

- Each State Planning Council shall conduct a review and analysis of the effectiveness of, and consumer satisfaction with . . . services . . . to all persons with developmental disabilities in the state. Such review and analysis shall be based upon a survey of a representative sample of persons with developmental disabilities receiving services . . . and their families, if appropriate.
- The state plan must include an analysis of . . . priority areas in relation to limited support or lack of support for persons with developmental disabilities attributable to physical impairment, persons with developmental disabilities attributable to mental impairment, and persons with developmental disabilities attributable to a combination of physical and mental impairments.

Public Forums will be held in cooperation with Legal Advocacy Services for Persons with Developmental Disabilities of the Disability Law Center in Minneapolis, which must also assemble a state plan for providing protection and advocacy services. Primarily the purpose of the public meetings will be to receive testimony from interested consumers, families, and others relating to priority needs. These meetings will also provide an opportunity to obtain comments from all interested

persons in the state regarding the unserved and underserved populations of persons with developmental disabilities which result from physical and mental impairments.

Each State Planning Council must select two or more of the federal priority areas for grant activities. The federal priorities are: community living, employment, child development, and case management. At its discretion, a State Planning Council may select different areas of activities, in addition to those prescribed in the Act. Sixty-five percent of the basic state grant must be expended for priority area activities, which include:

- Activities to increase the capacities and resources of public and private nonprofit entities and others to develop a system for providing specialized services or special adaptations of generic services or other assistance which responds to the needs and capabilities of persons with developmental disabilities and their families and to enhance coordination among entities;
- Conduct of studies and analyses; gathering of information; development of model policies and procedures; and presentation of information, models, findings, conclusions, and recommendation;
- Demonstration of new ways to enhance the independence, productivity, and integration into the community of persons with developmental disabilities;
- Outreach activities for persons with developmental disabilities to enable such persons to obtain assistance in federal priority areas or a state priority areas, including access to specialized services or special adaptations of generic services;
- Training of persons with developmental disabilities, family members, and personnel including professionals, paraprofessional, students, and volunteers, to obtain access to, or to provide services and other assistance for persons with developmental disabilities and their families; and
- Activities designed to prevent developmental disabilities from occurring or to expand and enhance the independence, productivity, and integration into the community of persons with developmental disabilities through the state on a comprehensive basis.

Through its surveys and public hearings, the Governor's Planning Council will prepare recommendations on how to remove barriers to services for persons with developmental disabilities.

The basic intent behind the Developmental Disabilities Act is to: 1) assure that persons with developmental disabilities receive the care, treatment, and other supports

VOLUNTEER SURVEY FORM

The Minnesota Planning Council on Developmental Disabilities is seeking volunteers to participate in a survey of people with disabilities and their families. The survey is to help meet the requirements as set forth in the Developmental Disabilities Assistance and Bill of Rights Act (P.L. 100- 146) in the preparation and submission of its Three-Year State Plan and a special 1990 report to Congress.

If you would like to participate, please send us your name, address, and telephone number(s). To help us in the sampling process, also please complete the questions below about the person with a disability. Individual rights to privacy and confidentiality will be protected.

 YES, PLEASE CONSIDER ME AND/OR MY FAMILY MEMBER(S) AS VOLUNTEERS IN THE CONSUMER SURVEY.

NAME: _____

ADDRESS: _____

_____ ZIP: _____

TELEPHONE(S): Home: () _____ Work: () _____

1. What is age of the individual that has a developmental disability? _____ years old.

2. What type of disability(ies) does this person have? (check all that apply)

- a. Mental Retardation
- b. Physical Impairment
- c. Emotional problems
- d. Other

Describe: _____

3. Where does this person with a developmental disability live?

- At home.
- In a community setting outside of the home.
- In a regional treatment center.
- Other (Describe) _____

Please fold, apply postage stamp, and send to the address on the reverse side of this page.

THANK YOU FOR YOUR COOPERATION!

**MINNESOTA GOVERNOR'S PLANNING COUNCIL
ON DEVELOPMENTAL DISABILITIES
300 Centennial Building
658 Cedar Street
St. Paul, Minnesota 55155**

necessary to enable them to achieve their maximum potential through increased independence, productivity, and integration into the community, and 2) to establish and operate a system which coordinates, monitors, plans, and evaluates services which ensures the protection of the legal and human rights of persons with developmental disabilities.

Please direct any questions regarding the above to: Governor's Planning Council on Developmental Disabilities; 300 Centennial Office Building; 658 Cedar Street; St. Paul, MN 55155. Tel. (612) 296-4018.

INTEGRATION VIDEO AVAILABLE: REGULAR LIVES

The Association for Persons with Severe Handicaps (TASH) recently announced that a new videotape has been approved for national airing by the Public Broadcasting System and is ready for distribution. The video called, Regular Lives, was funded by the U.S. Department of Education, TASH, and other organizations, including the Minnesota Governor's Planning Council on Developmental Disabilities.

The 28-minute documentary, which focuses on people with developmental disabilities in typical school, recreational, and work settings, is an affirmation that integration works. The three primary goals of the video are: to promote public education about the concept of integration; to train staff on the concept of integration; and to reach and educate parents, agencies, and community citizens on integration. Cost: \$30.00, plus \$4.50 shipping and handling. Send check or money order, or call in your Visa or Mastercard number to: WETA; Educational Activities; Box 2626; Washington, DC 20013. Tel. (800) 445-1964.

HOME MODIFICATION SERVICES AVAILABLE TO GREATER MINNESOTA, AS WELL

The article that appeared on the first page of the March issue of DD Information Exchange about the Home Modification Program at Courage Center did not explain that these services are also available outside of the Metropolitan area. As mentioned, the Courage Center Home Modification Program can assist persons needing adaptive living environments. Professional occupational therapists, physical therapists, and other appropriate staff can evaluate a person's needs to determine what modifications are appropriate. These might include the installation of grab bars, construction of a ramping system, or other alterations which encourage maximum independence and mobility by persons with disabilities. Several financial sources can be explored for possible assistance. For more information, contact: Shannon McGurran; Courage Center; 3915 Golden Valley Road; Golden Valley, MN 55422. Tel. (612) 588-0811.

PUBLICATIONS

Opportunity Knocking: The Story of Supported Employment. PACER Center, Inc., Minneapolis, 1988. This booklet is intended for parents of youth with severe disabilities, informing them about supported employment options. Supported employment is designed for people with severe disabilities who have traditionally been excluded from regular work settings because of their inability to perform competitive work and their need for life-long support. Chapters include: making jobs possible; moving into the community; a path for normalization; a comparison with traditional programs; support available through service providers; variety of supports needed by individuals; different kinds of supported employment positions; and questions often asked by parents, family members, and guardians. An appendix lists many resources and services available throughout the United States.

Cost: \$6.00; FREE to parents of youth with severe disabilities. Contact: PACER Center, Inc.; 4826 Chicago Avenue, South; Minneapolis, MN 55417-1055. Tel. (612) 827-2966.

Audio-Visual Catalog: Toward Excellence. This is an ever-expanding library of audio cassette tapes and videotapes that may be purchased at reasonable prices. General topics include: public relations and management; family support services; early intervention and preschool; employment; independence, integration, transitions, and community living; living arrangements; and rehabilitation technology. The Catalog may be ordered from: John Siepp; United Cerebral Palsy Associations; 1522 K Street, Northwest, Suite 1110; Washington, DC 20005. Tel. (800) USA-2UCP, toll free.

Improving Health Care for Children with Chronic Conditions: Guidelines for Families. A. Healy and J. A. Lewis-Beck, Iowa's University Affiliated Program, 1987. This booklet resulted from the Iowa Health Care Guidelines Project. It is intended to help families cope when a child has a chronic illness or disability. It suggests how to maintain a supportive home for other family members. It also provides many excellent resources for further assistance and guidance. Four basic principles of health care are outlined: 1) assure access to quality health services; 2) focus on the child and family unit; 3) support normal living patterns in the home and community; and 4) promote better health care for children in the future. With these principles in place, five major areas of activity or steps are identified for each set of guidelines.

To order, send check or money order for \$2.50 to: Campus Stores; 208, G.S.B.; The University of Iowa; Iowa City, Iowa 52242.

LENDING LIBRARY SELECTIONS

The State Developmental Disabilities (DD) Program Office has acquired several education, training and resource materials. The following materials may be borrowed from the State Office only, located at the address on the front sheet of the State Supplement section of this newsletter. Tel. (612) 296-4018.

Integration Action Group: Jenny's Story, (Videotape, 1/2 inch VHS, 15:27 minutes), Richmond Hill, Ontario, Canada, 1988. This videotape explores the insights, relationships, and emotions related to community integration and home school education for a Canadian teenager named Jenny. Jenny's parents, friends, and teachers talk about the impact Jenny's integration has had on their lives, and depicts Jenny in integrated situations that could be expected of any 15 year old. This is especially suitable for teenagers and young adults.

Parents Speak Out: Then and Now, (Second Edition), H. R. Turnbull III and A. P. Turnbull, Charles E. Merrill Publishing Company, 1985. This is a collection of powerful stories that describe how those who sought help

for persons with disabilities and their families, and those who tried to provide it, met with a mixture of success and failure. Since its first publication in 1978, there has been a stronger national commitment to the education of all children with disabilities and their integration into the mainstream of society. More recently, however, the decision not to sustain the life of newborns with disabilities has been publicly debated. The authors hope that this book will strengthen the commitment to improving the quality of life for persons with disabilities. Each story, the authors believe, refutes the idea that some lives are not worth living. Follow-up essays to the first edition provides pictures of life then and now. Each essay is followed by questions designed to help the reader analyze the writer's point of view and think about how people lived and, more to the point, how they might live.

Metropolitan Council DD Program
300 Metro Square Building
7th and Robert Streets
St. Paul, MN 55101

If you no longer wish to receive this newsletter, please call (612) 291-6364, or write to the DD Program, Metropolitan Council 300 Metro Square Bldg., St. Paul, MN 55101

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1988 AGENDA REALIZING THE VISION

Experience A Regular Life Space

Think about what you did yesterday or the day before. Where did you go? Whom did you see? How did you complete these activities? What did you do by yourself and what did you do with other people? What were things you chose to do because you wanted to do them and what things did you do because you had to do them? How many of your activities were completed with people with handicaps and how many were with people without handicaps?

For those who went to work, a typical day may have been like this: Rise to the clock radio, shower, dress and fix hair, prepare and/or eat breakfast, put clothes for cleaners in car, drive to gas station to fill up with gas, proceed to work, chat with co-workers at water cooler, work, coffee break with co-workers, drive to cleaners on lunch break, stop for ice cream cone, drive back to work, make appointments, finish work, stop at the grocery for a few items, and drive home. Now you may change clothes and get your neighbor to go out jogging, do a little gardening, read the newspaper, visit with some other neighbors, call a friend on the phone, have dinner and put the dishes away. About 11:00 p.m. you prepare for bed and retire for the evening.

What was your day like? You had to go to work because that's what most adults do and you accept that responsibility. But look at the opportunities for choicemaking you had during the day: chatting with co-workers, buying ice cream, jogging, reading, gardening, plus what to eat, what to wear, and when and in what order to do them. There were at least 10 different environments in your life and there were probably about 25 to 35 different individuals with whom you interacted. Probably none of them had a handicap unless you work in an agency that serves them.

What was your day like if you were a person with a severe developmental disability? You are awakened by a staff

counselor, dress (you showered at 4:00 p.m. the day before because it was convenient for staff), eat breakfast that was prepared for you, get on the school bus with five to seven of your homemates, go to the Developmental Achievement Center and attend five classes, eat lunch that was prepared for you by group home staff, take a walk in a park with ten other classmates, return home on the bus, shower, relax in front of TV, eat dinner prepared by group home staff, go in the group home van to a special religious class, dress for bed and retire at 9:00 p.m.

Your day was spent entirely with other persons with handicaps or with people paid to be with you. Your day is a schedule of activities over which you have little or no choice or flexibility. Lou Brown, Ph.D., University of Wisconsin at Madison and others have stated that "The more handicapped you are, the more vulnerable you are. The more vulnerable you are, the more you need to be with non-disabled peers—non-disabled peers who aren't paid to be with you."

The total life space and connectors in the community are so much fewer than for most individuals. It can improve illuminating to examine and compare the life space of a non-handicapped individual with that of a person with severe developmental disabilities. Life space refers to the people, places, activities, materials, attitudes, demands, and values that a person encounters each day, every hour, all year. Unfortunately persons with severe handicaps almost always experience substantially fewer normalized community environments than do their non-handicapped peers.

A study of life space can help us to:

- Arrange a reasonable array of environments for meaningful participation;
- Maximize communication between day and residential services;
- Realize productivity and actualization in a variety of environments;

Activities, notices, services, products, etc. mentioned in this publication are for information purposes only and do not imply endorsement by the Development Disabilities Programs of the Metropolitan Council and the State Planning Agency.

Expanding the life space experiences for persons with developmental disabilities can help to realize the vision of integration, not just physical but also social. Participation in society is developed by gaining confidence and competence in a variety of settings with a variety of people.

REMINDER -- Please return questionnaires on the DD Program-produced booklet called **The Case Management Team: Building Community Connections** to: Kay Zwernik, DD Program, Metropolitan Council, 300 Metro Square Building, St. Paul, MN 55101 as directed on the questionnaire by June 30. People still wishing to obtain a copy of the booklet for review may write to: Data Center, Metropolitan Council, 300 Metro Square Building, St. Paul, MN 55101.

VOUNTEERS NEEDED FOR COUNCIL'S DEVELOPMENTAL DISABILITIES ADVISORY COMMITTEE

The Metropolitan Council is taking applications from Twin Cities Metropolitan Area residents interested in serving on its *Developmental Disabilities Advisory Committee*.

The volunteer committee advises the Council on the needs of people with developmental disabilities and helps coordinate planning to meet those needs.

The 25-member committee is made up of persons who have developmental disabilities, their parents or guardians, service providers and the general public. Members serve three-year terms. There are 10 vacancies to be filled.

The committee usually meets the second Tuesday afternoon of every other month. Members are expected to serve on subcommittees. Members volunteer their time, but may be reimbursed for their expenses.

For applications or for more information call *Sandi Lindstrom* of the Council staff at 291-6390. Applications are due August 15, 1988. Appointments will be made by the Council on August 25 with new terms beginning October 1, 1988.

"Developmental disabilities" refer to chronic and severe physical or mental handicaps that are manifested before age 22 and that substantially limit functions in three or more basic living activities.

STUDY EXAMINES TRENDS IN SERVICES SPENDING

In the second edition of *Public Expenditures for Mental Retardation and Developmental Disabilities in the United States*, authors Richard Hemp, and Glenn Fujlura and

David Braddock updated and analyzed trends in state and federal funding across the 1977-1986 period for all states.

during that period was the dramatic growth of spending for community services in the states. In contrast, even though institutional per diems continued to rise--to \$127--the institutional sector was contracting proportionately with respect to the total MR/DD spending, and absolutely when expressed in economic terms. There were 100,421 residents of state institutions in 1986. Excluding federal income maintenance payments, the nation expended 2.5 times as much for institutional care in 1977 as it did for community services in facilities of all sizes. In 1986, however, the nation was spending approximately equal sums in both sectors, \$4.647 billion and \$4.422 billion, respectively.

Services for people with mental retardation and developmental disabilities were predominantly provided in large congregate care settings. Indeed, a second striking finding of the study was that fully 87 percent of all reimbursements budgeted under the Intermediate Care Facilities for Mental Retardation (ICF/MR) Program in 1986 went to congregate facilities with 16 beds or more. Seventy-five percent of 1986 ICF/MR reimbursements supported care in state-operated institutions and only 9 states were budgeting 25 percent or more of their total available ICF/MR resources in 1986 for small 15-bed or less facilities. Minnesota was one of those at 29 percent available for smaller facilities. No state budgeted as much as 50 percent of its total ICF/MR resources for 15-bed or less facilities. The large congregate care facility is the dominant ICF/MR model being used in the states.

States exhibit great variations in their committed resources to community-based services. Michigan and Illinois, for example, have many cultural, political, and demographic similarities such as population, income levels and urban-rural configuration. But the relative priority each state assigns to financing small-scale community-based services as opposed to large congregate care facilities is dramatically different. In 1986, Illinois spent \$230.2 million for care in state institutions and 16-bed or larger facilities. The state spent \$141.8 million for its remaining community-based services. In marked contrast, Michigan expended \$112.8 million in large congregate care settings (institutions only, since Michigan has no ICFs/MR of 16 beds or more) and \$276.7 million for community-based services.

Michigan and Illinois thus expended almost identical sums for total MR/DD services in all settings in 1986 (\$389 million versus \$372 million, respectfully), but the Michigan system was dominated by small-scale community services and the Illinois system by large congregate care facilities. The Michigan profile illustrates the fiscal consequences of implementing a strong community integration policy over a period of several years.

The 582-page monograph, which contains a ten-page analytical profile on each state, is available (ask for monograph #29) until the supply is exhausted by writing to: MR/DD Expenditure Analysis Project; Evaluation and Public Policy Analysis Program (m/c 627); University of Illinois at Chicago; 1640 West Roosevelt Rd.; Chicago IL 60608.

FOR YOUR INFORMATION

Direct Deposit of Social Security Benefits

Many people do not know they can have their Social Security or Supplemental Security Income checks sent directly to their bank or other financial institution. More than a third of Social Security and SSI beneficiaries, 17.5 million people, are utilizing direct bank deposit. People who use direct deposit avoid having to wait in line and the time and travel expenses necessary to cash or deposit a check. They also virtually eliminate the risk of a lost or stolen check. Individuals wishing to use the direct deposit service should contact their financial institution to make arrangements.

Summer Sign Language Program Available

St. Mary's Campus of the College of St. Catherine is offering Sign Language Immersion Programs I and II (SLIP). The two courses are designed for teachers and parents of hearing impaired children among others. The program is an intensive sign language course for people who want to learn sign language quickly and "painlessly". SLIP I will be held June 13 through July 8, Monday through Friday 9:00 a.m. to 3:30 p.m. The cost is \$250. SLIP II will be held July 11-22, the same days and hours and the cost is \$125. To register, contact: Health Care Interpreter Program; 2500 South 6th St.; Minneapolis, MN 55454 or 332-5521, ext. 218.

SERVICES

Girl Scouting Programs

A traditional activity for young girls has been to join the Girl Scouts. The Girl Scout Council of St. Croix Valley offers the opportunity for all girls between the ages of five and 17, regardless of physical or mental disability, to join the Girl Scouts.

The mission of the Girl Scouts is to help girls grow up to be caring, competent, confident women. The mission is achieved through adult-girl partnership with adult role models; girl involvement in planning, decision-making and evaluating; and working toward the Girl Scouts four goals: developing self-potential, relating to others, developing values, and contributing to society.

Girl Scouts make new friends. Throughout the year they participate in a variety of activities at age-level which could include camping, career exploration, international games, songs, dances, and food, puppetry, cookie sales or various environments.

The St. Croix Valley Council serves Anoka, Chisago, Dakota, Isanti, Pine, Ramsey and Washington counties. For more information contact: Girl Scout Council of St. Croix Valley; 400 South Robert; St. Paul, MN 55107 or 227-8835.

Residential Services Loan Money Available

Loan money to fund residential services for people with mental retardation within Hennepin County is available through the Association for Retarded Citizens of Hennepin County. There are two funds available:

1) Community Development Block Grant (CDBG) is available for programs located within the city of Minneapolis, and 2) ARC of Hennepin County Board Restricted money is available for programs located within Hennepin County. Possible uses for these loans might include start-up costs, renovations, equipment purchase, or down payment on a consumer or family-owned home. For further information and application procedures, contact: Ginny Gadbois Green; ARC of Hennepin County; 2344 Nicollet Ave. So. #370; Minneapolis, MN 55404, or 874-6650.

EMPLOYMENT OPPORTUNITIES

Job Coach--Train and supervise persons with mental retardation at community-based job sites. Full-time position available immediately. Experience with persons with mental retardation or industry-related job preferred. College credits or AA degree desired.

Community Integration Specialist-- This is a new position. Individual will assess, train and support persons with developmental disabilities with their use of community, leisure and other generic resources. Help facilitate the building of relationships with peers and co-workers. Minimum qualifications include: Four-year degree in a field related to Human Services. Two year's experience working with persons with mental retardation. Must have knowledge of integration, the normalization principle and community resources. Must be flexible with work schedule and be able to use own vehicle as needed. Full-time position available immediately.

Send resume for either of the above positions to: Kaposia, Inc.; 179 East Robie; St. Paul, MN 55107, Attention: Human Resources Coordinator.

PUBLICATIONS

Your Link is a new quarterly publication by the Interagency Planning Project for Young Children with Handicaps (IPPYCH). It features current information about Minnesota's efforts to successfully implement a "family-driven early intervention system" for infants and toddlers with handicaps or at risk and for their families. To get on the mailing list for the free newsletter, contact: "Your Link"; IPPYCH; 8th floor, Capitol Square Bldg.; 550 Cedar St.; St. Paul, MN 55101, or (612) 296-7032.

Based upon information collected through two statewide needs assessments, conferences and many other resources, the Interagency Steering Committee (ISC) of the Interagency Planning Project for Young Children with Handicaps and an advisory task force of direct service providers from throughout Minnesota have developed **Your Handbook: Guidelines for Designing Comprehensive Service Systems for Young Children with Handicaps.**

WORKSHOPS/CONFERENCES

Your Handbook provides quality indicators and a system overview in the areas of screening, referral, assessment, intervention, and evaluation. Each module also contains sections for sample forms and models. There are also modules on federal and state legislation, team process and resources available at the local, regional, state and national levels. The handbook is a resource designed to provide technical assistance and help develop linkages in the early intervention service system. To obtain a copy contact: IPPYCH; 8th floor, Capitol Square Building; 550 Cedar St.; St. Paul, MN 55101 or (612) 296-7032.

Simple Solutions to Difficult Problems of Handicap Access is a catalog providing a listing of products to aid in barrier removal such as door levers, parking signs, chair lifts, and grab bars among others. This catalog provides a photo of the product, its approximate price, and information on where it can be obtained. To order: Julie Quarve-Peterson, Inc.; P.O. Box 28093; Crystal, MN 55428. (\$35.00 includes postage and handling.)

Adaptive Garden Equipment Manual is written for consumers, families, and professionals as a resource for low-cost adaptation of garden equipment and lists adaptive equipment supply catalogs. For more information: Materials Management Division; Craig Hospital; 3425 South Clarkson; Englewood, CO 80110.

Disability Rights Guide: Practical Solutions to Problems Affecting People with Disabilities bridges the gap between legalistic rhetoric and basic English. It includes sections dealing with employment, accessibility, and architectural barriers, housing, education and transportation. For further information: Charles Goldman, Esq.; 1010 Vermont Ave. NW, Suite 1100; Washington, D.C. 20005.

"**The Teacher's Role**" is a newly revised pamphlet published by the Epilepsy Foundation of America to provide updated information about epilepsy for school teachers. It describes the various types of seizures and tells what the teacher should do if a child has a seizure in class and how the teacher can help the other children in the classroom understand what has happened. Single copies are available free from: Epilepsy Foundation of America; Materials Service Center; 4351 Garden City Drive; Landover, MD 20785. Bulk copies may be ordered at a nominal price.

An Advocate's Guide to Case Management Services in Minnesota is a publication of the Peer Advocacy Project of Legal Advocacy for Persons with Developmental Disabilities in Minnesota. The manual defines what case management is and who is eligible. In simple terms and illustrations the manual provides step-by-step guides to understanding what the various components of case management services in Minnesota are as specified in Rule 185 and how to obtain them. Also included is a guide to the appeals process at every step of the case management process. The manual is a part of the Metro Council DD Program library and may be borrowed by picking it up at: 300 Metro Square Building; 7th and Robert Streets; St. Paul, MN 55101 or by calling 291-6364.

June 14-16, 1988

"Supported Employment Dynamics" is a workshop designed to provide a complete and comprehensive program that addresses the essential components of successful supported employment. The workshop, sponsored by the Minnesota Developmental Achievement Center Association and the Staples Technical Institute, will be held at Madden's Inn, Brainerd, Minnesota. Faculty will include: Ian Pumpian, Professor at San Diego State University; Tom Power, Director of the Connecticut Supported Employment Corporation; and Mike Callahan, Project Director for the United Cerebral Palsy Association's National Demonstration Project on Supported Employment. For additional information, contact: MnDACA; 1821 University Avenue, suite 277; St. Paul, MN 55104. Tel. (612) 647-9200.

June 24 and 24, 1988

"National Interdisciplinary Seminar on Dual Diagnosis" will seek to define the term "dual diagnosis", identify therapeutic approaches in treatment, review recent research, identify behavior management techniques, evaluate need for psychotropic medication, and examine community integration and sexuality issues. This seminar is sponsored by the Blick Clinic. Registration fee is \$115. The site for the seminar is the Quaker Square Hilton in Akron, Ohio. For further information contact: Blick Clinic, Inc., Seminar Headquarters, 640 West Market Street, Akron, OH 44303 or (216) 762-5425.

July 9, 1988

"Working with the Medical Community" is a family education workshop sponsored by the ARC Suburban. Sally Swallen who coordinates "ASK ARC" and the Community Health Education Network for ARC Minnesota and has parented two sons with mental retardation will share her personal experience with various medical professionals as well as her work with the medical community. The workshop will be held from 10:00 am to noon at the United Way Multi-Service Center 14451 Co. Rd. 11 in Burnsville. There is a \$5 fee. For more information call ARC Suburban at 431-3700.

July 20-22, 1988

"Severely Handicapped/Sensory Impaired" is a three-day workshop covering the issues of instructional strategies for working with students with severe impairments, effects of environmental space, optimal classroom environments, collaboration between families and professionals, leisure and recreation skills, family adjustment, and the changing needs and roles of parents and professionals. The fee is \$90 for professionals and \$30 for students and parents. The location is the St. Paul Radisson, 11 East Kellogg, St. Paul, MN. For information or a brochure contact: Jan Hickey; University Press Building, 1st floor; 2037 University Ave. S.E.; Minneapolis, MN 55414 or call (612) 624-2016. This workshop is sponsored by the University Affiliated Program and the Department of Education.

June 1988

Developmental Disabilities Program
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Minnesota State Planning
Agency
Roger Strand, Editor

Member of
National Association of
Developmental Disabilities
Councils

'LRE' CONCEPT FULL OF FLAWS/ PITFALLS, SAYS STEVEN TAYLOR

"The principle of the least restrictive environment (LRE), sometimes referred to as LRA, or the least restrictive alternative, is conceptually and philosophically flawed," proclaimed Steven Taylor from the Research and Training Center on Community Integration at the Center on Human Policy, Syracuse University. His critical analysis appeared in an article entitled, "Caught in the Continuum: A Critical Analysis of the Principle of the Least Restrictive Environment," The Journal of the Association for Persons with Severe Handicaps, (Spring 1988), pp. 41-53.

"The principle of LRE was extremely forward-looking for its time," Taylor noted. "It emerged in an era in which persons with developmental disabilities and their families were offered segregation or nothing at all. As a legal concept and policy direction, LRE helped to create options and alternatives," Taylor further observed. However, Taylor then challenged, "It is time to find new ideas, concepts, and principles to guide us . . . We must define the challenge in terms of total integration for people with developmental disabilities."

Building on previous critiques of the continuum concept, the author presents seven serious conceptual and philosophical flaws or pitfalls in the LRE principle:

1. The LRE principle legitimates restrictive environments:

- It implies that there are circumstances under which the most restrictive environment would be appropriate.
- As long as services are conceptualized in this manner, some people will end up in restrictive environments—in most cases people with severe disabilities.

2. The LRE principle confuses segregation and integration on the one hand with intensity of services on the other:

- It assumes that the least restrictive, most integrated settings are incapable of providing the intensive services needed by people with severe disabilities.
- It follows that people with severe disabilities will require the most restrictive and segregated settings.
- However, segregation and integration on the one hand and intensity of services on the other are separate dimensions.

3. The LRE principle is based on a "Readiness Model":

- Implicit is the assumption that people with developmental disabilities must earn the right to move to the least restrictive environment. In other words, the person must "get ready" or "be prepared" to live, work, or go to school in integrated settings with many residential and vocational programs designed to be "transitional." The irony is that the most restrictive placements do not prepare people for the least restrictive placements.... Institutions do not prepare people for community living, segregated day programs do not prepare people for competitive work, and segregated schooling does not prepare students for integrated schooling

4. The LRE principle supports the primacy of professional decision making.

- According to Douglas Biklen (also at Syracuse University), integration is ultimately a moral and philosophical issue, not a professional one. Yet LRE invariably is framed in terms of professional judgments regarding "individual needs." The phrase "least restrictive environment" is almost always qualified with words such as "appropriate," "necessary," "feasible," and "possible" (and never with "desired" or "wanted"). "Professionals are left to determine what is appropriate, possible, feasible, or necessary for any particular individual," Taylor observed. (Continued on next page.)

5. The LRE principle sanctions infringements on people's rights.

- The question implied by LRE is not whether people with developmental disabilities should be restricted, but to what extent. Thus, the LRE principle sanctions infringements on basic rights to freedom and community participation beyond those (continued on next page)

SPECIAL ANNOUNCEMENT: A New Way of Thinking, videotape, will be aired on television on Sunday, June 12, 1988, 12:00 noon, on KARE 11, immediately following "Prism," KARE 11's public forum program. Help spread the word! This videotape was a cooperative project of the Governor's Planning Council on Developmental Disabilities and the Minnesota University Affiliated Program. The tape was recently selected for a "Gold Apple Award" by the National Education Film and Video Festival held in Oakland, California.

- imposed on people who are nondisabled. The principle becomes a tool to legitimate unnecessary segregation under the guise of protecting rights.
 - In regard to providing services, as distinguished from social control, people with developmental disabilities should have the opportunity to live, work, and go to school in "nonrestrictive environments"--that is, integrated settings--rather than "least restrictive" ones.
6. The LRE principle implies that people must move as they develop and change.
 - Even if people moved smoothly through a continuum, their lives would be a series of stops between transitional placements. This can destroy any sense of home and may disrupt relationships with roommates, neighbors, and friends.
 7. The LRE principle directs attention to physical settings rather than to the services and supports people need to be integrated into the community.
 - Gunnar Dybwad was quoted as saying, "Every time we identify a need in this field, we build a building." By its name, the principle of the least restrictive environment emphasizes facilities and environments designed specifically for people with developmental disabilities.
3. From professional judgment as a basis for determining community involvement to personal choice;
 4. From a presumption in favor of integration to a mandate to provide opportunities for integration;
 5. From a conditional ("to the extent necessary, appropriate, feasible") to an unconditional commitment to integration;
 6. From requiring individuals to change in order to participate in the community to requiring service systems to change;
 7. From restrictions applied categorically as a condition for receiving services to opportunities available to nondisabled people;
 8. From disability labels as a factor in determining community participation to a recognition of common human needs;
 9. From independence to community belonging; and
 10. From placing people in the community to helping them become part of the community.

Taylor cautions his readers by adding, "The concepts that guide us today can mislead us tomorrow.... If and when integration is achieved, we must be prepared to find new ideas and principles to guide us through the challenges and dilemmas we undoubtedly will face."

Requests for reprints of the article should be sent to Steven J. Taylor, Ph.D., Center on Human Policy, Syracuse University, 724 Comstock Avenue, Syracuse, NY 13244.

Taylor contends that we are, indeed, caught in the continuum model by not critically examining the principle of the least restrictive environment. What is happening is that a new "community-based" continuum is being created. "Conceptually, this community-based continuum suffers from many of the same flaws that characterize the traditional continuum," Taylor observed. He then suggested, "The progressive leadership of the field today does not intend to establish a new continuum of services, but instead to outline an array of options, some of which happen to be more restrictive and less integrated than others."

Taylor then suggests a policy direction--total integration, which means "the elimination of social, cultural, economic, and administrative barriers to community integration and the design of services and supports to encourage, rather than discourage, involvement in community life and to cultivate, rather than impede, relationships between people with developmental disabilities and people who are not disabled."

Contrasted with the LRE principle, a commitment to integration requires a shift in focus:

1. From the development of facilities and programs into which people must fit to the provision of services and supports necessary for people with severe disabilities to participate fully in community life;
2. From neighborhoods to typical homes, from regular school buildings to regular classes, and from vocational models to typical jobs and activities;

UNIVERSITY OF MINNESOTA ANNOUNCES COMMUNITY INTEGRATION GRANT AWARD

The Educational Psychology department at the University of Minnesota, in collaboration with Syracuse University and the University of Illinois-Chicago, recently announced the establishment of a Rehabilitation Research and Training Center (RRTC) on Community Integration. The Center, funded by the National Institute on Disabilities and Rehabilitation Research, is scheduled to begin operation in June of 1988.

The new center will focus on research, training, and dissemination activities that will facilitate the integration of persons with mental retardation, including those with severe handicaps. The RRTC will study five areas: (1) community living arrangements; (2) financial support; (3) extended service options and opportunities for community integration; (4) social skills and interpersonal relationships; and (5) personal independence and choice. In addition, the RRTC will develop local model programs, disseminate information about best practices, and provide training and technical assistance. Professor Robert H. Bruininks will serve as the director. For further information, please call (612) 624-4848.

VOLUNTEER SURVEY FORM

The Minnesota Planning Council on Developmental Disabilities is seeking volunteers to participate in a survey of people with disabilities and their families. The survey is to help meet the requirements as set forth in the Developmental Disabilities Assistance and Bill of Rights Act (P.L. 100- 146) in the preparation and submission of its Three-Year State Plan and a special 1990 report to Congress.

If you would like to participate, please send us your name, address, and telephone number(s). To help us in the sampling process, also please complete the questions below about the person with a disability. Individual rights to privacy and confidentiality will be protected.

 YES, PLEASE CONSIDER ME AND/OR MY FAMILY MEMBER(S) AS VOLUNTEERS IN THE CONSUMER SURVEY.

NAME: _____

ADDRESS: _____

_____ ZIP: _____

TELEPHONE(S): Home: () _____ Work: () _____

1. What is age of the individual that has a developmental disability? _____ years old.

2. What type of disability(ies) does this person have? (check all that apply)

- a. Mental Retardation
- b. Physical impairment
- c. Emotional problems
- d. Other

Describe: _____

3. Where does this person with a developmental disability live?

- At home.
- In a community setting outside of the home. .
- In a regional treatment center.
- Other (Describe) _____

Please fold, apply postage stamp, and send to the address on the reverse side of this page.

THANK YOU FOR YOUR COOPERATION!

Place
Stamp
Here

**MINNESOTA GOVERNOR'S PLANNING COUNCIL
ON DEVELOPMENTAL DISABILITIES
300 Centennial Building
658 Cedar Street
St. Paul, Minnesota 55155**

NEW VIDEOTAPE ON TECHNOLOGY AVAILABLE

A new videotape entitled "Tools for Life: How Technology Helps People with Disabilities" is available from the Governor's Planning Council on Developmental Disabilities. This new videotape was produced with financial assistance from the McKnight Foundation. The videotape shows a student, a lobbyist, and an entrepreneur, each with a disability, who have been able to become more independent and productive because of the availability of technological devices. The videotape is not copyrighted and borrowers are encouraged to make copies for their own use. To borrow a copy, contact: Governor's Planning Council on Developmental Disabilities; 300 Centennial Office Building; 658 Cedar Street; St. Paul, Minnesota 55155. Tel. (612) 296-4018

PUBLIC FORUMS SCHEDULED

Public Forums have been scheduled throughout the state during the last three weeks of July 1988 by the Governor's Planning Council on Developmental Disabilities and Legal Advocacy Services. These Forums are being held to gather data for the next three-year state plan and for a report to the Governor, Legislature, and Congress. People are invited to present testimony that will reflect their views, experiences, and recommendations about policies and services affecting persons with severe disabilities and their families.

People providing testimony will be asked to respond to four questions:

- What priority should the Council select for the next three-year plan? What is the rationale for this choice? (The federal priorities are: 1) case management; 2) child development; 3) community living; and 4) employment activities. The state may also select its own priority.)
- What are the needs of people who are underserved and unserved?
- What other recommendations should be included in a 1990 report to the Governor, Legislature, and Congress?
- What recommendations do you have for legal advocacy?

The schedule for the Public Forums is as follows:

JULY 12

Virginia	Mesabi Community College, Rm 90 9th and W. Chestnut	7:00 p.m.
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JULY 13

International Falls	Rainy River Community College, Library	2:30 p.m.
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JULY 14

Grand Rapids	Itasca County Court House, Board Room	2:30 p.m.
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JULY 19

Brainerd	Brainerd Community College, Room 106 College Drive	7:00 p.m.
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Grand Marais	Grand Marais Library Second Ave. and W. First St.	7:00 p.m.
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Montevideo	Royal Inn Downtown	7:00 p.m.
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JULY 20

Duluth	University of Minnesota-- Duluth, Kirby Student Center, Rm 333	2:30 p.m.
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St. Cloud	St. Cloud State University Education Bldg., Rm A 110	2:30 p.m.
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Worthington	Worthington Community College, Rm 212, 1450 College Way	7:00 p.m.
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JULY 21

New Ulm	Holiday Inn 2101 South Broadway	2:30 p.m.
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JULY 25

Winona	Winona State University Student Union, Dining Room E	7:00 p.m.
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JULY 26

Albert Lea	Albert Lea Technical Institute, Rm 153 2200 Tech Drive	2:30 p.m.
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Bemidji	Bemidji State University Hobson Memorial Union South Conference Room	7:00 p.m.
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JULY 27

Crookston	University of Minnesota Food Service Bldg., Rm 131	2:30 p.m.
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JULY 28

Fergus Falls	Fergus Falls Community College, Administration Building, Rm A-303	2:30 p.m.
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St. Paul	Centennial Office Bldg. Conference Rm 300	2:30 p.m.
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LENDING LIBRARY SELECTIONS

The State Developmental Disabilities (DD) Program Office has acquired several education, training and resource materials. The following materials may be borrowed from the State Office only, located at the address on the front sheet of the State Supplement section of this newsletter. Tel. (612) 296-4018.

Transitions to Adult Life for People with Mental Retardation: Principles and Practices. B. L. Ludlow, A. P. Turnbull, & R. Luckasson (Eds.), Paul H. Brookes Publishing Company, 1988. This is a book about the transition from school to independent living, community participation, and productive employment by young adults with mental retardation. Practical application of information from diverse perspectives is meaningful to both policymakers and service providers. Solutions are offered for overcoming common problems resulting from a fragmented service system and the lack of communication among programs and disciplines. "How to" suggestions are provided for designing, implementing, and evaluating transition programs. Many well known authors contributed chapters that comprise the following sections: concepts and trends; programming goals and strategies; and legal and administrative issues. Appendices include: an annotated bibliography, media resources, and a directory of transition programs that provide: research and technical assistance; direct services; and personnel preparation.

Community Recreation and Persons with Disabilities: Strategies for Integration. S. J. Schleien & T. Ray, Paul H. Brookes Publishing Company, 1988. This book provides both the conceptual framework and the specifics of application relative to integrated leisure life-styles for persons with disabilities. Concepts that are presented may be readily applied to the challenge of developing programs that are meaningful and accessible for all people—not just individuals with disabilities. Following a thorough presentation of the planning process, the authors address the issues of environmental assessment and modification, behavioral analysis and functional growth, and the evaluation process, with specific attention to the cognitive, affective, and psychomotor domains. Case studies provided in the final chapter illustrate concepts and approaches in a community settings. This book focuses on a "systems change" approach away from a segregated system and into an integrated system—addressing the needs of all individuals. "No longer can society afford to exclude people from programs based on their special needs," the authors stated.

People interested in purchasing these selections may contact the publisher (Paul H. Brookes Publishing Company) directly by calling: (800) 638-3775.

Metropolitan Council DD Program
300 Metro Square Building
7th and Robert Streets
St. Paul, MN 55101

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INFORMATION EXCHANGE

*Published monthly by the Developmental Disabilities Program of the Metropolitan Council
Editor: Kay Zwernik*

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1988 AGENDA REALIZING THE VISION

Relationships

In the spring of 1986 Christine Dols was 13 and attended a program for children labeled as Trainable Mentally Handicapped (TMH) in an elementary school. Her teacher informed the Special Education Director that Christine would be 14 in the fall and not age-appropriate for that program any longer. The school district decided that Christine was eligible for the secondary TMH program which was located in the AVTI in Dakota County and made that decision based on assessment information two years old.

Christine's mother, Roby, toured the school where her daughter would attend the following September and became concerned about what it could offer Christine. The school stands in an isolated area surrounded by farms and is two miles from any businesses. The non-handicapped students who attend there do so for only a couple hours and the full-time students are adults. Few eat lunch in the lunchroom. There are no extra curricular activities. The TMH rooms are in a corner of the building, and there is a separate gym with the letters TMH on the door. Mrs. Dols saw no equipment in the gym. The TMH students have their own yearbook and prom. Used formals are sought through newspaper ads. By September Mrs. Dols decided she did not want Christine to attend this school and withdrew her consent.

Mrs. Dols's primary interest was that Christine attend an age-appropriate school in her own neighborhood so that she would be a part of her community and would have contact with non-handicapped peers on a regular basis. At a team meeting several options were discussed for Christine. The options presented were not acceptable to Roby Dols because of age-inappropriateness or long

distance from home. At this point a friend suggested to Roby Dols that she contact Larry Ringer at Legal Advocacy. Larry attended two conciliation conferences with Mrs. Dols. Finally, it was agreed that Christine would go on an interim basis to a junior high school several communities away and that some integration experiences would be arranged. In late September Christine began to attend school. Mrs. Dols continued to advocate for an in-district placement at an age-appropriate school for Christine and the school district continued to state that the junior high in another community was appropriate.

Postponements and more postponements of integrated activities, assessments to be completed, and answers to letters, etc. proved to be frustrating for the Dols family. Christine spent part of her year with homebound education due to surgery. In May of 1987 the school district again recommended placement at the AVTI for Christine, for the 1987-88 school year and the family requested a due process hearing which took place during the summer. The Administrative Law Judge concluded that the school district had failed to provide Christine with an appropriate IEP, and appropriate educational services in the least restrictive environment. Christine began attending Rosemount Senior High School in the fall of 1987.

The "hardest part is sending her to a place you know isn't good for her, that she didn't want to go to, and that she came home stressed out and didn't like her day" said Mrs. Dols. Now that she's going to the Senior High in her home community, she said, Christine goes out and sits on the front steps and waits for the bus. At the junior high in another community, she had no friends, because the distance for parents to drive was too great. She didn't see any of her schoolmates when she was in the community, and she couldn't get involved in after-school activities because the activity bus wouldn't come to her community. On her last day at the junior high, she wore her Rosemount team jacket.

Activities, notices, services, products, etc. mentioned in this publication are for information purposes only and do not imply endorsement by the Development Disabilities Programs of the Metropolitan Council and the State Planning Agency.

Christine has now completed her first year at Rosemount High. What was her experience? Her special education teacher said it took a lot of time and effort to make all the arrangements and connections for her initially, but throughout the year things have been smooth. Different students volunteered to meet her at the bus and walk her to her classroom. Throughout her day Christine was constantly around non-handicapped peers, in the hallways, at lunch, on the regular school bus, at pep rallies, and in classes. She also had a full-time aide. Although she was described as having "behavior problems" in the segregated classes, the "behaviors" disappeared when she was in integrated settings, and if something she did was inappropriate, her peers told her to "cut it out." Christine attended football games, the band show, plays, ice skating show, and other activities fellow students normally attend. She received vocational experiences in the fine dining cafeteria, a grocery store, a laundry, and in running messages.

Beth Mount, a consultant who is one of the leaders nationally in futures planning for people, says that in her experience with thousands of people with disabilities the most important thing for them are relationships. The other facets like training and work do not rate as high as having friends, someone to talk to on the phone, to eat with in a restaurant, to just be around someone who cares but isn't paid to come to your door. Probably the most important thing for Christine in her first year of high school were the friends she made, the relationships she developed with peers her own age.

During the second trimester Christine took aerobics. Guys and gals in the class befriended her. For the final, small groups of students had to create an exercise routine. Several groups, including boys, asked Christine to be a part of their group.

When Christine was in the community shopping or out to dinner, fellow students would greet her and stop to chat, asking how she was, introducing her to their own families, or complimenting her on her clothing. This was possible because she was attending her own local school.

Initially in the lunch room Christine and her aide sat by themselves at a table. By the end of the the year, there were two tables of peers every day sitting with Christine. (The aide had to find another place to sit.)

During the third trimester, Christine took a weight training class. At the end, students were asked if Christine had been any problem in the class and had she and they learned anything from her participation. The responses were very positive. One day a week the students decided to play softball. Due to a vision problem, Christine could not see the fast ball. So that she could be included in the game with them, the students set up a 'T' for her.

Christine donned her first formal and nylons plus eye shadow and lipstick to attend the Sno Days formal dance at school. Her mother didn't see her for an hour at a time that evening because her fellow students kept whisking

her away to dance and to mix with the other boys and girls.

School years end with the signing of autographs in yearbooks. This year end was no different for Christine who has many signatures of fellow students on her autograph pages. The following is typical:

You are a wonderful person and a great friend.
Take care of yourself and be good to everyone.
Hope to see you next year. Stay sweet. Love Kym
Class of '89

Relationships Christine is developing now will support her throughout her life, in her work, in her leisure time, as a member of her community. A petite, friendly, and outgoing young lady is realizing her vision of an integrated education. Way to go, Christine!

FUTURE OF THERAPEUTIC SERVICES FOR YOUNG CHILDREN, Submitted by ROBERTA A. KREB, M.S., CCC SPEECH-LANGUAGE PATHOLOGIST

The developmental achievement center is closing. How does a young child get the therapeutic intervention services they are entitled to under the law?

In 1987, the legislature passed a law that affects all children with any form of handicap in the State of Minnesota. Effective with the 1988 school year, local school districts are responsible for the provision of "educational" services to children ages birth to 21 years who meet their criteria levels. "Educational" services do not have to include rehabilitative therapeutic intervention. Most school districts provide no physical therapy to preschoolers and occupational therapy and speech-language pathology services may be the consultative model versus direct treatment.

Currently, there are no mandatory guidelines in regard to the type or model of services provided to preschool children by the public schools. The legislative mandate suggests a homebased model for servicing the needs of the birth to 3 year old population. The only additional funds provided to school districts to enable them to serve children birth to 3 years old with special needs are transportation funds.

The suggested "State criteria" for early intervention services by the school district implies that only those children who are severely handicapped will get intervention. A child will have to score on formal testing which are 1.5 to 2.0 or more standard deviations below the mean. Children who may require therapeutic intervention and are not severely handicapped may not be eligible for services through the public schools.

In the past, developmental achievement and learning centers have provided both the educational and therapeutic intervention services for children with handicaps. The Developmental Achievement Center has acted as the coordinator for these children's special

needs. Most DACs have contracted for therapeutic interventions services from private agencies. Through contracting, DACs were assured...quality service by appropriately trained and certified professionals. (Most costs were paid by third-party sources.)

Parents and families must now assume the total responsibility of advocating for services for their children. Parents and families must request the therapeutic intervention services their children are entitled to receive (physical therapy, occupational therapy, speech-language pathology and psychosocial). Services and models for delivery vary by school district dependent upon the needs of each child and the school districts available resources. Children with special needs require a transdisciplinary involvement. Parents and families must assume an advocacy role to ensure appropriate and continuing services. If the local school district cannot provide services, parents and families must look elsewhere to the private agencies. Parents and families are encouraged to contact area professionals or their children's current service provider to ensure continuing and appropriate services for their children. Only parents and families can make the difference in the services and the model of delivery their children will receive now and in the future.

VOLUNTEERS NEEDED FOR COUNCIL'S DEVELOPMENTAL DISABILITIES ADVISORY COMMITTEE

The Metropolitan Council is taking applications from Twin Cities Metropolitan Area residents interested in serving on its Developmental Disabilities Advisory Committee.

The volunteer committee advises the Council on the needs of people with developmental disabilities and helps coordinate planning to meet those needs.

The 25-member committee is made up of persons who have developmental disabilities, their parents or guardians, service providers and the general public. Members serve three-year terms. There are 10 vacancies to be filled.

The committee usually meets the second Tuesday afternoon of every other month. Members are expected to serve on subcommittees. Members volunteer their time, but may be reimbursed for their expenses.

For applications or for more information, call Sandi Lindstrom of the Council staff at 291-6390. Applications are due September 9, 1988. Appointments will be made by the Council on September 22 with new terms beginning October 1, 1988.

"Developmental disabilities" refer to chronic and severe physical or mental handicaps that are manifested before age 22 and that substantially limit functions in three or more basic living activities.

SURVEY OF ATTITUDES ABOUT EPILEPSY

A recent Gallup poll of American attitudes toward people with epilepsy shows that stigma is still a problem. Fully one third (33 percent) of those surveyed who were aware of epilepsy believe that having the disorder makes others think less of you. However, two-thirds said that having epilepsy does not make other people think less of you or your family. The survey was prepared by the Gallup Organization, Inc., for Parke-Davis, consisting of telephone interviews with 1,000 people. Over 20 questions were asked in the interview.

Approximately 9 in 10 Americans think people with epilepsy whose seizures are under control and are qualified could be employed in supervisory positions, in food handling jobs, as school teachers, and as elected officials and politicians. The majority do not think they should be employed as bus or truck drivers. The public has mixed emotions about whether or not people with epilepsy should drive automobiles. Four in 10 (44%) say they should not drive cars; half (51%) say they should.

POLL ASKS PEOPLE WITH DISABILITIES ABOUT THEIR PARTICIPATION IN ELECTIONS

Americans with disabilities show a "significantly higher level of interest in politics, governmental affairs and public affairs than Americans in general, but they do not register and vote at correspondingly high rates." This is the principle result of a recent Harris Poll. People with disabilities have twice as much interest in governmental and public affairs as other citizens (53 versus 26 percent) but people with disabilities register to vote at a rate that is six points lower than the general population and they vote at a rate that is 12 points lower than the general population.

The findings suggest that barriers, either external or internal or both, prevent many Americans with disabilities from converting their exceptionally high political interest into actual electoral activity. The Harris study was based on interviews with 536 adults with disabilities across the U.S. during June and July, 1987.

Other findings of the Harris Poll were:

- The ratio of partisans to independents (65 versus 31 percent) is exactly the same among citizens with disabilities as it is for all U.S. adults.
- 84 percent said they consider a candidate's position on disability issues when making voting decisions.
- 63 percent said they are frustrated in efforts to learn of candidates' positions in the area of disability.
- Americans with disabilities appear to be somewhat less trusting of government. They also are less likely to feel that they have a "say" in what their government does.
- The large majority (73 percent) said they prefer to vote in the traditional way inside the polling place.

19 percent said they prefer to cast an absentee ballot.

- Two key findings suggest that if it were not for the substantial barriers that still remain, Americans with disabilities should be expected to register and vote at rates that would be significantly higher than the rest of the population.
- Young adults who have disabilities have especially low participation rates. This pattern is also true of young adults generally in the U.S. population, but disability compounds the issue of registration.
- The lesser educated among people with a disability also have especially low participation rates. This is also true for those with less education in the general population, but disability compounds the disadvantage of the less educated even further.

Overall the survey reflects progress toward the goals of full participation by people with disabilities in political life, but it also shows there is much to be done throughout the country to ensure greater participation.

FOR YOUR INFORMATION

Cable Program on Disability

The Minnesota State Council on Disability presents TV CONNECTOR which is seen on Twin Cities Regional Cable on Channel 6 and on Continental TV on Tuesdays at 6:00 p.m. At other locations throughout the state consult your local cable station for viewing time. The CONNECTOR addresses current issues that are of importance to the 600,000 citizens in Minnesota who have a disability. The program is made possible through a grant from the Northstar Chapter of the Multiple Sclerosis Society.

Parents Helping Parents

The Minnesota Early Learning Design (MELD) is a Twin Cities program that provides information and support to parents. MELD Special groups offer information and support to parents of children who have disabilities or are chronically ill. The group focuses on the "ordinary" tasks of raising a child, such as child development, sibling issues, and childcare. Meetings are held every other week in the evening. Parents continue to participate with the same group for one to two years. Childcare is provided on site. Private foundation support enables parents to participate in MELD Special at no charge. For more information about groups, dates, and locations, contact MELD at 612/332-7563.

PUBLICATIONS

Warning Signals: Basic Criteria for Tracking At-Risk Infants and Toddlers by James Blackman is a booklet of criteria for use in identifying and evaluating infants who are at risk of developing a disability. The booklet, developed under the auspices of the National Center for Clinical Infant Programs, is recommended for parents,

professionals, policymakers, and administrators. For a free copy contact: National Maternal and Child Health Clearinghouse, 38th and R Streets, N.W., Washington, D.C. 20057.

WORKSHOPS/CONFERENCES

August 1-5, 1988

Rural Infant Institute. National Speakers have been invited to present information on best practices in working with infants who are handicapped and their families to a symposium titled "Infants/Families/Professionals: Perspectives and Strategies for Intervention." The symposium will take place at St. John's University in Collegeville, Minnesota. Two credits or audits are available as are student stipends. For more information, contact Joan Blaska 612/255-3251.

September 26-27, 1988

The Office of Continuing Medical Education of the University of Michigan Medical School is sponsoring a course/conference entitled, "Sexual Exploitation of Persons with Disabilities," to be held at the Michigan League, University of Michigan in Ann Arbor. Faculty from the United States and Canada will discuss issues and develop further strategies for preventing sexual exploitation of people with disabilities. Contact: Gayle Fox; Office of Continuing Medical Education; Towsley Center-Box 0201; University of Michigan Medical School; Ann Arbor, MI 48109-0201. Tel. (313) 763-1400.

September 28-30, 1988

The Third Annual National Community Integration Forum, "Philosophy, Practice, Personhood: Achieving a Balance," will be held at the Concourse Hotel in Madison, Wisconsin. The Forum will have three tracks: managing community services, self-advocacy, and community supports. Emphasis will be placed on support over systems, of choice over compliance, and personhood over programs. For more information and registration forms, contact: New Concepts, 7425 University Avenue, Middleton, WI 53562. Tel. (608) 831-1221.

EMPLOYMENT OPPORTUNITIES

Program Coordinator - Responsible for managing and developing a growing training and habilitation program currently consisting of 10 staff persons and recruiting, hiring, training, and evaluating progress of all staff, quality control for all client program plans, and monitoring program compliance with all state and federal rules and regulations. Desirable qualifications include a four-year degree in human services, five years experience working with adults with developmental disabilities, and 2 years supervisory experience. Full-time position with competitive salary and benefits. Range \$17,000-19,500. Send resume to Careers Training Center, 415 North Grove Ave., Owatonna, MN 55060 by July 11, 1988. Phone: 507/451-5897.

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Councils

MINNESOTA RANKS LOW ON INTEGRATION OF STUDENTS WITH HANDICAPS

Although the least restrictive environment (LRE) provision in the Education for all Handicapped Children's Act (P.L. 94-142), creates a presumption in favor of educating children with handicaps in regular education environments, a recent report indicated that there is considerable variation among states, which demonstrates the potential for improvement in the national effort to educate children with handicaps in less restrictive environments. The report also indicated that the use of separate educational environments has been relatively stable over the last decade. The report, entitled, "State Variation in Placement of Children with Handicaps in Segregated Environments," was written by Louis C. Danilson, and G. Thomas Bellamy of the Office of Special Education Programs (OSEP), U.S. Department of Education, Washington, DC.

Each year states submit data to OSEP on the number of children with handicaps who are served in each of six different educational placements: regular class, resource room, separate class, separate day school, separate residential school, and home/hospital. Over the past decade, 1976-87, there was little change in the use of separate facilities for students with handicaps, the authors observed. Although there was an increase in the use of regular class placements, this trend probably reflected the increase in numbers of students with learning disabilities.

In order to compare state placement patterns, a statistic called, "cumulative placement rate," was computed: using the number of special education students aged 6-17 years in a state who were served in a selected educational placement and all more segregated placements divided by the state's total population in this age group.

The study revealed that in the most recent school year (1986-87), "Over 225,000 students, or 6 percent of all students with handicaps, were educated in programs outside the regular school building."

There were another 24 percent of students with handicaps who were educated in regular school buildings but were served primarily in segregated classes. Combining this with the regular class and resource room figures revealed that 94 percent of the children with handicaps were educated in regular school buildings.

Nearly 44 percent of the students with handicaps were served in resource rooms with another 26 percent served in regular classes. Consequently, over 70 percent of the students counted in special education spend substantial amounts of time in regular education classes, the authors observed.

Expressed as a function of the resident population of the United States, 6- to 17-year-old children were placed in separate facilities at a national rate of approximately 3,800 per one million of same-aged resident population. The placement of school-aged students in residential facilities occurred at a rate of approximately 970 per million of same-aged population. The combined rate of placement in segregated facilities was over 4,800 students per million of same-aged population.

When comparing states regarding the placement rate for students with handicaps in separate schools and residential facilities, the state of Oregon had a rate of 6,600 children per million, or the lowest use of separate schools and residential facilities. At the other end of the chart was the District of Columbia, with a rate of 15,000 children per million, 25 times the rate of Oregon.

On this ranking, Minnesota was tenth from the bottom, with approximately 7,500 children per million.

Ten states with the highest cumulative placement rate in separate classes were also among the 10 states with the highest placement rate for segregated facilities.

On another scale (placement rate for students with handicaps in separate classes, separate schools, and residential facilities), Minnesota placed twentieth from the top state (Oregon), which had the highest degree of integration.

The authors concluded that some states have been more successful than others in providing services in regular settings that were seen as appropriate by local decisionmakers. OSEP will be working with individual states to improve reporting methods as well as to examine state variability and variances.

Copies of the complete report are available upon request from: Governor's Planning Council on Developmental Disabilities; 300 Centennial Office Building; 658 Cedar Street; St. Paul, Minnesota 55155. Tel. (612) 296-4018.

AMERICANS WITH DISABILITIES ACT OF 1988 INTRODUCED IN CONGRESS: DIARIES OF DISCRIMINATION REQUESTED

In late April 1988, the Americans with Disabilities Act of 1988 (H.R. 498) was introduced in Congress. This bill, which was conceived by the National Council on the Handicapped, seeks to establish a comprehensive national mandate to eliminate discrimination against persons with disabilities.

Stated in a letter to members of Congress by the Consortium for Citizens with Developmental Disabilities on May 12, 1988, was this plea: "It is time for this country to address the reality that Americans with disabilities are relegated to second-class citizenship. This long overdue legislation simply states that people with disabilities are entitled to the same rights that all other Americans take for granted-- the right to communicate, the right to work, the right to live in the community, and the right to socialize."

"Despite the landmark antidiscrimination provisions under Section 504 of the Rehabilitation Act of 1973, many people with disabilities have great difficulty obtaining jobs, finding housing, traveling from place to place, and functioning in many other aspects of daily life that most citizens take for granted," said Christina Metzler of the National Association of Developmental Disabilities Councils (NADDC). "One of the many reasons for these problems is that Section 504 only applies to federally conducted or assisted programs, thus leaving most of the private sector and state and local governments immune from handicapped antidiscrimination coverage," Metzler added.

The proposed legislation would guarantee the same federal civil rights protections that are enjoyed by women and by other minority groups; Americans with disabilities are not covered by Title II or Title VII of the Civil Rights Act of 1964 or by Title VIII of the Civil Rights Act of 1968. The Americans with Disabilities Act of 1988 would seek to correct this inequity.

Among the types of discriminatory practices prohibited under the legislation would be the:

- failure to address architectural, transportation, and communication barriers;
 - use of discriminatory qualifications, standards, or eligibility criteria; and
 - denial of equal opportunity based on a relationship or association with persons with disabilities.
- The proposed legislation specifies several federal agencies that would be called upon to promulgate and enforce relevant guidelines and regulations. It also contains necessary enforcement procedures as administrative remedies, a private right of action, monetary damages, injunctive relief, attorneys' fees, and the cutoff of federal funds.
- According to an announcement from the Consortium for Citizens with Developmental Disabilities, "Enactment of this legislation will be a long struggle. The key to its eventual passage is education of our constituencies, the general public, and Members of Congress." People who have a disability are urged to keep a "Discrimination Diary," or write their personal experiences of discrimination in a letter. All diaries and letters should include the writer's name, full address, and if possible, the name of their Congressman. Please send them to: Diaries; c/o Disabled but Able to Vote; 2111 Wilson Blvd., Suite 400; Arlington, VA 22201. (Samples of how discriminatory practices affect people's lives and how to keep a diary may be requested by writing to this same address.)

NEW ADD COMMISSIONER

Carolyn Doppelt Gray has been named Commissioner of the Administration on Developmental Disabilities (Washington, DC) following the death of Commissioner Lucy Biggs.

Prior to her appointment, Gray was the Acting Deputy Assistant Secretary for the Health and Human Services Office of Human Development.

RESEARCH ASSISTANT POSITIONS AVAILABLE

There are five to seven research assistant positions open at the University of Minnesota for students who wish to pursue a graduate degree in a field related to developmental disabilities. These positions range from ten to twenty paid hours per week and carry a partial to full tuition reimbursement, depending on appointment. For further information, please contact Mary Linz or Carol Werdin at (612) 624-4848.

BRUININKS ELECTED TO AAMR POST

Robert H. Bruininks, Ph.D., a professor in the Educational Psychology Department at the University of Minnesota, has been elected First Vice President and President-Elect of the American Association of Mental Retardation.

Bruininks is the director of the Minnesota University Affiliated Program on Developmental Disabilities and of the Center for Residential and Community Services at the University.

PUBLICATIONS

Opening the Doors to Independent Living and Teaching Materials (Teacher's Guide), Sandra Anderson, Metropolitan Center for Independent Living, St. Paul, Minnesota, 1988. This is a guide for high school students who have a disability and for their teachers. It is a publication by the Metropolitan Center for Independent Living, funded by the Minnesota Department of Education, intended to reach students at the age when they are making decisions about their future. This publication will complement programs already being offered to students in the schools. It deals with those areas often found to be most problematic when making the transition to community living such as attendant care management, housing, transportation, leisure activities, and one's self-worth. Topics covered in this manual are presented as goals necessary for accomplishing greater independence. The author states, "It is hoped the information presented will encourage those who read it to take a good look at their wishes and desires, and realize that their goals can be accomplished." The cost for each manual is \$2.50, or \$5.00 for the two booklets, payable to: Metropolitan Center for Independent Living, Inc.; 1619 Dayton Avenue, Suite 303; St. Paul, MN 55104. Tel. (612) 646-8342.

Family-Centered Care for Children with Special Health Care Needs, T. L. Shelton, E. S. Jeppson, B. H. Johnson, Association for the Care of Children's Health, 1987. This publication presents eight components that have been identified by parents and professionals across the country as key elements of a family-centered approach to care for children with chronic illnesses and disabling conditions. The elements convey a new philosophy of care--moving from an institution/agency approach, to a child-centered approach, and most recently to a family-centered approach.

As the sun became the center of the universe rather than the earth in the Copernican Revolution, so is the placement of the family at the center of the service delivery system perceived as revolutionary among health care providers. This approach shifts the emphasis from that of requiring parental involvement (i.e., parents participating in the program) to providing family support (i.e., programs providing a range of support services to families).

The eight elements of family-centered care identified were:

1. Recognition that the family is the constant in the child's life while the service systems and

personnel within those systems fluctuate;

2. Facilitation of parent/professional collaboration at all levels of health care;
3. Sharing of unbiased and complete information with parents about their child's care on an ongoing basis in an appropriate and supportive manner;
4. Implementation of appropriate policies and programs that are comprehensive and provide emotional and financial support to meet the needs of families;
5. Recognition of family strengths and individuality and respect for different methods of coping;
6. Understanding and incorporating the developmental needs of infants, children and adolescents and their families into health care delivery systems;
7. Encouragement and facilitation of parent-to-parent support; and
8. Assurance that the design of health care delivery systems is flexible, accessible, and responsive to family needs.

For copies, contact: Association for the Care of Children's Health; 3615 Wisconsin Avenue, Northwest; Washington, DC 20016. Tel. (202) 244-1801.

Life Lines: People with Disabilities Speak Out, L. I. Isaacs & J. A. Clark, Massachusetts Developmental Disabilities Council, 1988. This booklet summarizes fifty interviews conducted with people with developmental disabilities and their family members as part of an awareness project in Massachusetts. Their stories reflected many troubles, remarkable solutions, and a disturbing number of defeats in seeking education, employment, respite care, and a variety of other services. Their collected stories reveal that a service system has been created that often lacks accessibility and coherence.

"At times needed services simply do not exist," the authors observed. "The single most frustrating and anxiety-producing part of having a child with a disability is not the child, but getting services to meet his/her needs," the authors added. Having a case management system would be an effective way to integrate relevant agencies and provide flexible, coordinated services, while respecting the competence, autonomy, and dignity of citizens with disabilities, the authors concluded. For copies of the report, contact: Massachusetts Developmental Disabilities Council; 600 Washington Street, Room 670; Boston, MA 02111. Tel. (617) 727-6374.

The State Developmental Disabilities (DD) Program Office has acquired several education, training and resource materials. The following materials may be borrowed from the State Office only, located at the address on the front sheet of the State Supplement section of this newsletter. Tel. (612) 296-4018.

LENDING LIBRARY SELECTIONS

Rethinking Architecture: Design Students and Physically Disabled People, Raymond Lifchez, University of California Press, Berkley, 1987. This book, available in paperback, examines an innovative and provocative experiment in architectural education. In an effort to develop a curriculum that was sensitive to the needs and challenges of people with disabilities, the author brought individuals with disabilities into the studio classroom as design consultants. As observed by the author, "In the past twenty-five years people with disabilities have become among the most vocal groups to protest the ways in which our society has attempted to exclude them, and they have pointed to the architectural environment as the most obvious symbol of how people who are able-bodied handicap those with disabilities. By working side-by-side with the design consultants, the architectural students not only learned a valuable professional lesson about client accommodation but also a profound personal lesson about human vulnerability and humility."

Can We Prevent Abuse and Neglect in Human Services?, Clarence J. Sundram, videotape (VHS-1/2 inch), St. Paul, Minnesota, 1988. This is a videotape recording of a presentation given by Clarence J. Sundram, Chair of the New York Commission on Quality Care. He spoke at a special seminar held at the Holiday Inn State Capitol in St. Paul on May 31, 1988. Speaking as a lawyer interested in human rights, Sundram asked, "How much abuse and neglect occurs?" That question cannot be answered. Attention is paid only when there are exposes, special inquiries, or undercover reports: . . . Reducing abuse is not a priority; there is little incentive to do so." He went on to suggest methods for reducing abuse through improved practices, such as: personnel recruitment, improving status of jobs, staff training, interaction and presence of supervisors, environmental improvements, prevention of burnout among employees, and conducting investigations by well trained individuals. He noted that the highest rates of abuse occur during idle time.

Metropolitan Council DD Program
Mears Park Centre
230 East Fifth Street
St. Paul, MN 55101

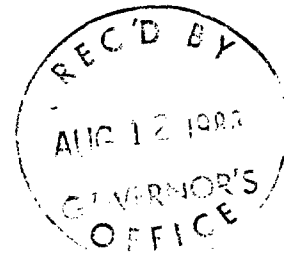
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INFORMATION EXCHANGE



*Published monthly by the Developmental Disabilities Program of the Metropolitan Council
Editor: Kay Zwernik*

**Metropolitan Council
Mears Park Centre
230 East Fifth Street
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**Vol. 13, No. 8
August 1988**

Note: The Metropolitan Council has moved to new offices. Please change our new address in your records. Two historic buildings facing Mears Park in downtown St. Paul were renovated to hold the Metropolitan Council, the Regional Transit Board, and the Metropolitan Waste Control Commission. The three agencies occupy all seven floors of the new quarters which house over 400 employees.

1988 AGENDA REALIZING THE VISION

Personal Futures Planning

The Developmental Disabilities Program of the Metropolitan Council has a grant for Fiscal Year 1988 from the Governor's Planning Council on Developmental Disabilities to produce a videotape and a guidebook about Personal Futures Planning. The first product of this project, the videotape, is now completed and ready for distribution. It's title is "It's Never Too Early, It's Never Too Late."

Personal Futures Planning (PFP) is a process of looking at the relationships, experiences, gifts, and capacities that an individual has in order to develop a vision for the future. Beth Mount of West Hartford, CT is one of the leaders in this country and Canada in developing and promoting PFP. This process is different from traditional or blueprint planning for individuals in that it focuses on designing a future around an individual, helping them become a part of community. Traditional or blueprint planning has relied upon assessments which are aimed at identifying deficiencies in an individual. Once the deficiencies are known, then professionals set out to fix or cure them. This is done by plugging people into slots in programs which

have been designed to provide people-fixing services. These programs are usually restrictive and segregated. Most individuals do not themselves decide to enter these programs or to receive these services. Those decisions are made by professionals.

Personal futures planning, on the other hand, centers on a focus person and seeks to clarify what goals they have for their life. A positive future is a summary of the experiences the group wants the focus person to have as a lifestyle. The vision of the future is a summary of the opportunities and capacities to work for the person in their connections with family, friends, and staff in the community and in the resources and opportunities in the service system. This vision of the future is continually revised as new opportunities arise and new barriers are encountered.

Planning a future for an individual uses a network of people who are close to the individual and who know him/her well to assist them in identifying significant things and events in their life and then to help in creating a future direction for the focus person. This network is sometimes also called a person-centered team or a circle of support. The circle or network also assists the individual achieving the goals they have set for themselves. Through regular meetings they seek to keep the goals on target and overcome obstacles that may arise.

The process of personal future planning proceeds through two meetings. The first meeting is held to develop a profile of the person. The purpose of the profile is to create a common understanding of the person, their environments and connections. That meeting should be personal and intimate, including individuals who know the individual well and know the folklore about the person. The meeting lays the foundation for the planning meeting. It helps to form a strong sense about the individual and a shared understanding of who that person is.

Activities, notices, services, products, etc. mentioned in this publication are for information purposes only and do not imply endorsement by the Development Disabilities Programs of the Metropolitan Council and the State Planning Agency.

At the planning meeting there are often more people involved, sometimes those identified in the profile. They are invited to the planning meeting because they may influence the outcome of the plan. In the planning meeting all the issues are brought together and then the group becomes realistic and pragmatic and starts to work out the details of how to make things happen. Also at this meeting a small group of people are identified to become the person-centered team or circle of support.

Unique to this process is the use of pictures, colors, and graphics in developing maps about the person on paper taped to the wall. Beth Mount has found that these are important because this process is designed to include people with disabilities. She feels that people with disabilities understand the pictures and the colors much more than they do either writing or just discussion. These help the person get involved even though they don't always understand exactly what's being written or what's being drawn. They also help people get creative and enthusiastic about the person.

One of the exciting things that happens during this process is that people discover so much more capacity in the individual that they had not been paying attention to previously. The format, the development of maps about the person, influences this change. Traditional assessment procedures do not have a format that focuses on capacities; instead they identify things a person can not do. With PFP so many positive things are found to work with that had not been noticed before, and that opens the door to so many opportunities for focus.

The ultimate goal of personal futures planning is full participation in community life. The person's circle of support assists in developing connections or bridges to community in order to make that happen. This group is very important because, if they meet regularly over time, not waiting three or six months, it is more likely that the plan will be actualized. Thus, there are actually three main pieces to the process: 1) the profile which means getting to know the person, 2) the plan which is developing strategies for action, and 3) the network group which meets over time after the plan is done to re-strategize and to brainstorm.

The fifteen-minute videotape "It's Never Too Early, It's Never Too Late" may be borrowed from Metropolitan Council by persons living in the seven county Metro area by calling the Data Center at 291-6464 to reserve it. For persons outside the Metro area contact the Governor's Planning Council on Developmental Disabilities at (612) 296-4018. Individuals may make their own copy of the video for their personal use.

RESPONSE TO LETTER IN JULY ISSUE

Editor's Note: Last month an opinion and statement about the impact of the new early intervention law to provide educational services by school district to children from

birth to 21 was published in this newsletter. It was written by Roberta Krebs, a speech pathologist in private practice. A reply to this article included this month is contributed by Sue Abderholden, Executive Director, ARC Minnesota. She states that while there can be problems with implementation of a new bill such as this, the ARC supports this new direction.

Ms. Abderholden offers the following comments:

1. The first early intervention law was passed in 1985, requiring school districts to provide educational services to all children with handicaps age three and above. That same law mandated the establishment of Early Intervention Committees that looked at the needs of children with handicaps beginning at birth. Thus, every district began planning in 1985.

2. The 1987 law mandated services beginning at birth beginning on July 1, 1988, which is prior to the 1988/89 school year.

3. Most school districts do provide occupational therapy and physical therapy services to pre-schoolers, as evidenced by the programs that were in place prior to the mandate (approximately 220 school districts provided services prior to 1985). Additionally, these staff are usually already in the district because of the needs of children over age five.

4. Educational services can include rehabilitative therapeutic intervention if the child needs this service and it is listed in the Individualized Education Plan.

5. (The) article implied that the consultation model is inferior to direct therapy services. The ARC would challenge this and believes that in some situations the consultative model can actually provide a greater amount of service.

6. Additional funds were appropriated for early intervention services. There are funds for special transportation, home-based travel, foundation aid, and reimbursement for special education teachers and staff. All of the funding mechanisms available for students with handicaps over age five are available for children with handicaps under age five.

7. While it is true that there are some children with mild handicaps who may not be served in the education system, they may be able to receive services through county funding. The maintenance of effort language and language found in Chapter 576 of 1988 clearly state that counties have a responsibility for funding and providing early intervention services. Early intervention services do mean more than educational services.

8. Parents and families have always had to assume the total responsibility of advocating for their children. Prior to 1985 there were only slightly over 20 developmental achievement centers providing early intervention services and they were only providing services to children with

mental retardation. Only one-third of all the children with handicaps were receiving early intervention services. Additionally, parents and children, under the DAC/county based system, had few rights compared to the education system. To imply that now, because of the change in the law, parents have the overwhelming task of being advocates for their children, is simply false.

9. Services and models vary by district based on the needs of children and all of the available resources in the community, not just in the district.

FOR YOUR INFORMATION

Respite Providers Meet Monthly

A group of statewide respite care providers meets on the last Friday of every month at 10:00 a.m. at the offices of the Association of Residential Resources in Minnesota (ARRM) in St. Paul. Their address is 245 East Sixth Street and is located in downtown St. Paul. The group meets to share ideas and provide information, discuss issues and concerns, and determine resolutions for issues specific to providers of respite care in Minnesota. For more information contact: Sandy Van Der Bosch at 1 (800) 551-2211 or Shelle McCue at (612) 424-1469.

Technology Tapes Available

TECH TAPES is a telemessage service of the Council on Exceptional Children's Center for Special Education Technology which users can access by calling toll free. Messages cover national resources, special education organizations, networks and data bases, computers and children with learning disabilities as well as teacher and administrator resources in technology. Individual messages include, among others, Parents' Primer on Buying Software (#353), Overview of Assistive Devices (#341), and Searching for ID Software (#325). To use TECH TAPES call: 1 (800)-345-TECH, except between 2:00 and 5:00 p.m. EST Monday through Friday. All other times you may access the tapes. To receive a TECH TAPES menu, write to the Center at: CEC, 1920 Association Blvd., Reston, VA 22091 or call the number above between 1:00 and 6:00 p.m. EST.

Foster Homes in Short Supply

Children and adults of all ages are placed in FOSTER HOMES in Scott County. Currently there is a severe shortage of homes to provide 1) SPECIAL NEEDS CARE for children with physical handicaps and/or mental retardation who need short-term "respite care" and/or longer term care and 2) ADULT FOSTER CARE for persons with physical, intellectual and/or emotional disabilities who could benefit from living in a community and family setting.

Who can be FOSTER PROVIDERS? Single people. Married people. Older people. Younger people. People who own their own homes and those who rent. What providers have in common is that they can offer an emotionally healthy, even tempered and flexible

environment to children or adults who cannot remain in their current living situation.

If you have hands-on experience, interest and/or a strong desire to learn about working with children or adults with disabilities, FOSTER CARE may be for you. For more information about any of Scott County's Foster Care Programs, call Linda Plessner at (612) 937-6505.

RESOURCES

Accessibility and Vacations

The Minnesota Travel Information Center has a publication which provides information about Minnesota's accessible state parks, residential camps, sports activities and special events. The guide which is titled "Explore Minnesota Accessibility" is free and available by calling the Travel Information Center at (612) 296-5029 or writing to them: Minnesota Travel Information Center, Bremer Building, 7th Place & Minnesota, St. Paul, MN 55101.

SKIP Publishes Family Support Handbook

Sick Kids need Involved People, Inc. (SKIP) now has available a new family support handbook entitled, "Families to Families: The Home Care Experience." The handbook offers an insight for families dealing with: 1. Sharing Our Feelings 2. I Want to Take Her Home But How? 3. Preparing for Home 4. Now That You Are Home 5. Looking Toward the Future 6. When Something Goes Wrong 7. Is It My Turn To Help? The handbook by Karen A. Shannon, Linda Jennings, R.N., and Karen Crawley Buckholtz, was written for families who have children with disabilities that often require medical management support. The handbook is available through SKIP, Inc., 216 Newport Drive, Severna Park, MD 21146 for \$7.50 which covers postage and handling.

Vocational Resources for Parents

"The Employment Project for Persons with Disabilities, How-To Booklet" informs interested persons of the efforts of a group of parents in Glen Ellyn, IL who in 1979 formed an information and support group. In 1982 they started an employment project with parents as volunteers to place into local jobs people whose handicaps prevented them from obtaining or retaining competitive employment on their own. The target population was graduates from special education programs. The booklet is available at no charge from: Special Education Parents Alliance, 305 22nd Street, Suite K-164, Glen Ellyn, IL 60137. (312) 790-3060.

"Young Adults with Learning Disabilities and Other Special Needs" is a paper which has a special section addressing parents' reaction to transition from school to work. It reviews guidelines for joint planning with a young adult toward increasing independence and relates observations about appropriate timing. The paper written by Ann R. Davie is available at no charge from: National Information Center for Children and Youth with Handicaps

(NICHCY), Box 1492, Washington, DC 20013. To leave a request for materials call toll free to: (800) 999-5599.

ARC-USA Develops New Publications

The ARC-USA had made available several new publications which the public may obtain at no charge. These are additions to the "arcfacts" series. * "Facts about HIB Disease" is about Haemophilus influenzae type b which causes several serious and often life-threatening illnesses. One of these, bacterial meningitis, may cause mental retardation in young children. * "Fragile X Syndrome" discusses this inherited genetic condition associated with mental retardation. * "Employment of People with Mental Retardation" explores job types and answers employer's questions concerning the hiring of people with mental retardation. * "Family Support" examines public and private services designed to assist families who wish to keep a member with mental retardation at home.

To receive any of these publications or a current ARC publications list, send a request along with a stamped, self-addressed envelope to: ARC Publications, Association for Retarded Citizens, National Headquarters, P.O. Box 6109, Arlington, TX 76005.

REQUEST FOR INFORMATION

The Minnesota Association for Persons with Severe Handicaps is making a request of readers of this newsletter. **SHARE YOUR UNKNOWN STORIES!** A committee is currently in the planning stages of some conference presentations and a publication. The Committee would like to include the successes or the partial successes from around the state. What is a success? It is a challenge that has been presented to staff or a family regarding an individual with developmental disabilities. It is the way that challenge was addressed and the forward and sometimes backward progress made regarding that challenge. The end result is greater participation in community life, development of relationships, employment on a job, attendance at school in a regular class or something else that led to a greater quality of life for the person with developmental disabilities. Jot down a few sentences or a few pages and share them with the chapter so other people in this state can know about your progress. Only first names or pseudonyms of people with developmental disabilities will be used. Writers names will be used if permission is given. Please send the stories to: Anita Schermer, 2129 Eleanor, St. Paul, MN 55116.

WORKSHOPS/CONFERENCES

August 19-21, 1988

"Gearing up for Integration" is the title of the ARC Minnesota convention designed to integrate people with mental retardation into the community. This convention will focus entirely on integration issues giving families,

consumers and professionals the tools necessary to fulfill that mission. Dave Hasbury, senior associate of the Centre for Integrated Education in Canada will give the keynote address called "Circles of Support, Creating places where dreams can be shared." The convention will be held at St. Cloud State University Atwood Center. Registration is \$30 for members and \$42 for non-members. For more information: ARC Minnesota, 3225 Lyndale Avenue South, Minneapolis, MN 55408 or (612) 827-5641.

August 11, 1988

August 19, 1988

The Minnesota AIDS Project is sponsoring workshops for human service professionals to update participants on current AIDS information and to teach skills and strategies for client AIDS education. It is assumed that participants will have a basic knowledge of AIDS. The workshop on August 11 is for professionals working in the field of physical disability, and the one on the 19th is for those in the field of mental retardation. The workshops run from 9:00 a.m. to 5:00 p.m. and the fee is \$25 per workshop. They will be held at the Minnesota AIDS Project offices at 2025 Nicollet Ave. So. in Minneapolis. Call (612) 870-7773 to register.

August 19, 1988

"Physical Intervention Alternative" is a workshop on managing challenging behaviors. It stresses non-violence and ways to avoid possibilities for physical abuse. The workshop will be held at the Ramada Hotel, 4200 West 78th Street in Bloomington from 9:00 a.m. to 5:00 p.m. Registration is \$75. For more information contact: REM, 6921 York Ave. So., Edina, MN 55435 or (612) 925-5067 or toll free (800) 682-3824.

September 20-21, 1988

A two-day workshop on program development strategies that enable individuals with even the most severe behavioral and learning problems to participate in their communities is the topic of a workshop titled "Community Based Instruction". Anne M. Donnellan, professor in Special Education and Rehabilitation Psychology at the University of Wisconsin-Madison is the presenter. The workshop will be held at the Sheraton Airport Hotel, 2525 East 78th Street in Bloomington. The fee is \$75. For more information contact: REM, 6921 York Ave. So., Edina, MN 55435 or (612) 925-5067 or toll free (800) 682-3824.

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Councils

IOWA SENATOR HARKIN INTRODUCES TECHNOLOGY-RELATED ASSISTANCE FOR INDIVIDUALS WITH DISABILITIES ACT

On June 23, 1988, Senator Tom Harkin (Iowa), Chair of the Subcommittee on the Handicapped, introduced S. 2561, the Technology-Related Assistance for Individuals with Disabilities Act of 1988. "We all depend on technology every day," he noted in his message to Congress. "From toasters to computers, technological advances make our lives easier at home, work, and play. For some individuals with disabilities, the provision of assistive technology devices can play a particularly critical role by enabling them to have greater control over their lives; participate in activities in their home, community, and school and work settings; and benefit from opportunities that are taken for granted by individuals who do not have disabilities."

The bill has two titles. The primary purpose of Title I is to assist states to develop and implement consumer-responsive statewide programs of technology-related assistance for individuals with disabilities so that such individuals may acquire information about and obtain assistive technology devices and services. It also authorizes the Secretary of Education to provide technical assistance to assist state to respond fully and effectively to the charge to develop statewide programs. States would be phased in through a competitive process: up to 10 states would enter the program the first year, 20 additional states the second year, and the remaining states the third year.

This legislation would function as a catalyst for increasing the availability of and funding (both public and private) for assistive technology devices and services. States would be given considerable discretion in setting up statewide programs and may elect to establish such functions as: identification and evaluation of needs; provision of assistive technology devices and services; dissemination of information; training and technical assistance; a public awareness program; assistance to community-based organizations; partnerships and cooperative initiatives; collection of program data; and procedures for involvement of concerned individuals.

Title II would authorize a variety of discretionary activities and studies, including a study of the financing of assistive technology and services, and a study of the feasibility and desirability of establishing a national information and

programmatic referral network on technology-related assistance. It also would support training and public awareness grants to increase the knowledge and effective use of assistive technology devices related to model projects for delivery of technology-related assistance, applied research and development in assistive technology devices and services, and a loan program for assistive technology devices.

On May 20, 1988, Rachel Wobschall, Director of the Minnesota Governor's Initiative on Technology for People with Disabilities, testified before the Subcommittee on the Handicapped. She told the subcommittee, "Technology is an equalizer that offers the means to compensate for limitations imposed by a variety of disabilities. It is a tool that can be used in all areas of life: in vocational, educational and recreational pursuits as well as in a variety of daily living situations throughout an individual's life span." She emphasized, "Legislation that creates the incentive for a coalition of consumers, producers, advocates, and professionals supplied with funding directed to the acquisition of assistive devices is an important first step in helping states provide technology for people with disabilities."

For a summary of this landmark legislation, contact: Rachel Wobschall, Director, Office of Technology and Disability, Governor's Office of Science and Technology, Department of Trade and Economic Development, 900 American Center Building, 150 East Kellogg Boulevard, St. Paul, MN 55101. Tel. (612) 297-1554.

PRESIDENT REAGAN ANNOUNCES COMMITTEE NAME CHANGE

On May 10, 1988, President Reagan signed an Executive Order that changed the name of the President's Committee on Employment of the Handicapped to the **President's Committee on Employment of People with Disabilities**. The announcement of the Executive Order carried the following explanation, "Our new name thrusts the President's Committee firmly into the forefront of awareness of the sensitivities of people with disabilities, people who refuse to be lumped together as 'the handicapped' or in other derogatory ways."

ACCESSIBLE HOMES--KEY TO INDEPENDENCE, PRODUCTIVITY, AND SAFETY

How many people with physical disabilities are living in homes that were never designed for them in the first place? How many would be able to work if they could get in and out of their homes with greater ease? How many people live in constant terror because of unsafe situations in their environment, particularly in bathrooms? As described by one architect who has a physical disability, Ron Mace, of Raleigh, North Carolina, stated "For too long, life has been a Monopoly game in which people with disabilities are not allowed to pass 'go'" (Paraplegia News, January 1986, p. 30). Many of these concerns were highlighted at an institute held February 19 and 20, 1988, "Modifications in the Home," at the United Cerebral Palsy Office of New York City.

"Project Open House and Family Support Services" is a project that was created in the mid-1970s at the United Cerebral Palsy of New York City in cooperation with the New York City Department of Housing Preservation and Development and the Mayor's Office for the Handicapped. The program was designed to remove architectural barriers in residential situations throughout the five Boroughs of New York City, serving people with mobility impairments of all ages, and who have low and moderate incomes. The goal of the program is to facilitate independent (or less dependent) living for persons with disabilities by reducing physical and environmental barriers to community living.

Between 1980 and 1985, architectural barriers were removed from over 750 homes at the cost of approximately \$1,200 per dwelling. This one time expenditure permitted people to remain in their communities and maintain close contact with their families. "In sum," claimed Marcia Eppler-Colvin, Consultant with Project Open House, "the government saw an annual savings of \$30,000 to \$100,000 per person, which does not even include the immeasurable values of the greater independence experienced by persons with disabilities or greater freedoms realized by the other family members."

Upon initial application and acceptance into the program, the following services are provided:

- The home is evaluated by an occupational therapist and social worker. The person with a mobility impairment, family members, medical and/or therapy staff are considered in the assessment, including: a) client abilities and disabilities; b) client and family needs, requirements, and priorities; c) national standards for barrier free design; d) funding limitations (\$2,500 maximum per family); e) environmental circumstances and constraints; and f) clinical recommendations of evaluator and primary medical team.

- A proposal (scope of work) is then written, based on the evaluation results. A social worker will advocate with the landlord for permission to do work. Typical alterations include (but are not limited to) widening of doorways, installation of grab bars and ramps, bathroom and kitchen adaptations, emergency equipment, environmental control systems, etc.
- Three estimates are solicited to ensure cost-efficiency and high quality of work.
- Permission to do renovations is granted by administering city agencies. (New York has extremely progressive state and city building codes.)
- Equipment is purchased by the Open House Program.
- The contractor performs renovations as per scope of work under the supervision of project staff.
- Clinical and/or technical staff inspect work and collect certificate of completion from the client.
- Follow-up home training in use of equipment and modifications is provided in the following areas: activities of daily living, homemaking, transfer training, mobility training, personal health and safety, and use of equipment.

"Demands for services are overwhelming," exclaimed Eppler-Colvin. A waiting list of 575 people is not uncommon. **Many wait for two years for a visit to their home.** By that time, they have often forgotten that they had applied. Current funding allotments of \$2,500 per family often prove insufficient for major structural modifications. "Clearly, increased private and community support is essential for effective provision of these accessibility and support services," she concluded.

For more information about Project Open House, contact: POH; United Cerebral Palsy of New York City; 122 East 23rd Street; New York, NY 10016. Tel. (212) 677-7400.

NATIONAL ALLIANCE AIMS AT BROAD DISABILITY ISSUES

The National Citizen's Alliance on Disability Issues, Inc. (the Alliance) is a non-partisan, non-profit, grass-roots membership organization that exists to enhance and encourage the informed participation of persons with disabilities, their families, service providers, advocates, and others in the political processes of the United States. The Alliance is a new group that wants to be able to hold elected officials accountable for the positions they articulate on disability issues as candidates.

Ed Roberts, current President of the World Institute on Disability and one of the Alliance founders said that the organization was formed in the belief that disability issues

are political issues just like labor issues, woman's issues, and issues which address world peace and military strength." He gave as example, "There are 36 million Americans with disabilities for whom issues such as access to public transportation for people with physical disabilities, community based living options for people with developmental disabilities, and reduction of the staggering-- reportedly 60 percent--unemployment in this population are very important."

For a membership application or more information on the National Citizen's Alliance on Disability Issues, Inc., please write or call: The Alliance; Box 141159- Beechwood Station, Columbus, Ohio 43214. Tel. (614) 267-0895.

MCKNIGHT FOUNDATION SEEKS AWARD NOMINATIONS

Nomination forms for the 1988 McKnight Awards in Human Service are now available. The purpose of the awards is to recognize those individuals throughout the State of Minnesota who are making significant contributions in the human service areas by directly assisting others to become productive and participating members of the communities in which they reside.

In this fourth annual series of awards, ten individuals will be selected to receive awards of \$5,000 each. The goal of the program is to reward those persons who are doing the difficult jobs and tasks with a minimum of public recognition and with a minimum of financial remuneration.

To be considered for this award, nominees must be involved in direct service, on a voluntary or paid basis, either full-time or part-time. Their work must be characterized by exceptional personal commitment. **The deadline for the submission of nominations is September 30, 1988.** The awards will be announced on or before December 1, 1988.

Individuals wishing to nominate a candidate for one of these awards should call or write: The McKnight Foundation; 410 Peavey Building; Minneapolis, MN 55402. Tel. (612) 333-4220.

MINNESOTA UAP APPROVED FOR NEXT THREE YEARS

The Minnesota University Affiliated Program (MUAP) on Developmental Disabilities has recently been awarded a three-year continuation contract by the Department of Health and Human Services in Washington, DC. The mission of the MUAP is to apply its resources to improve the quality and community orientation of professional services and social supports available to individuals with developmental disabilities and their families. The newly approved funding enables the MUAP to continue its extensive involvement in promoting interdisciplinary training, technical assistance, research, and dissemination activities in the area of developmental disabilities throughout Minnesota. For more information, contact: Carol Werdin; MUAP; University of Minnesota; 6

Pattee Hall; 150 Pillsbury Drive, SE; Minneapolis, MN 55455. Tel. (612) 624-4848.

MINNESOTA UAP INTRODUCES NEW CURRICULUM

The Minnesota University Affiliated Program on Developmental Disabilities has introduced a new sequence of courses in interdisciplinary study of developmental disabilities. Unique to the preparation of these courses has been the collaboration of eleven different academic units at the University. Adaptive physical education and recreation, health, and social work are some of the departments which have contributed their expertise in defining the courses and bringing their particular perspectives to students through readings, lectures, and panel discussions. Students may take single courses of interest or may complete a 16-credit sequence of required courses and internship to receive a Certificate of Interdisciplinary Studies in Developmental Disabilities.

Following is a list of new courses offered (3 credits each) and the quarters in which they will be offered during the 1988-89 academic year:

- EPsy 5609, Family-Professional Planning for Persons with Severe Handicaps, Fall 1988;
- EPsy 5710, Contemporary Services for Persons with Developmental Disabilities, Fall 1988;
- EPsy 8603, Services for Persons with Developmental Disabilities: Research and Policy Analysis, Spring 1989;
- EPsy 8770, Intervention Strategies for Persons with Developmental Disabilities: Interdisciplinary Perspectives, Winter 1989.

For more information, contact: Minnesota University Affiliated Program; University of Minnesota; 6 Pattee Hall; 150 Pillsbury Drive, Southeast; Minneapolis, MN 55455. Tel. (612) 624-4848.

CONFERENCE

October 20-22, 1988

Closing the Gap will be presenting its sixth annual international conference, "Microcomputer Technology in Special Education and Rehabilitation." Preconference sessions will be offered on October 18 and 19. Conference headquarters will be at the Radisson South Hotel in Bloomington, Minnesota. For more information, contact: Closing the Gap, P.O. Box 68, Henderson, MN 56044. Tel. (612) 248-3294.

The State Developmental Disabilities (DD) Program Office has acquired several education, training and resource materials. The following materials may be borrowed from the State Office only, located at the address on the front sheet of the State Supplement section of this newsletter. Tel. (612) 296-4018.

LENDING LIBRARY SELECTIONS

Regular Lives, (VHS 1/2inch), The Association for Persons with Severe Handicaps and Syracuse University, 1988. This 28-minute documentary, which focuses on people with developmental disabilities in typical school, recreational, and work settings, is an affirmation that integration works. The three primary goals of the videotape production are: to promote public education about the concept of integration; to train staff on the concept of integration; and to reach and educate parents, agencies, and community citizens on integration.

Special note: The Association for Persons with Severe Handicaps (TASH) recently announced that **Regular Lives** has been approved for national airing by the Public Broadcasting System and will be broadcasted nationally during the week of September, 19-23, 1988. This production was funded by the U.S. Department of Education, TASH, and other contributors, such as the Minnesota Governor's Planning Council on Developmental Disabilities.

Those who wish to purchase this videotape may do so by sending a check or money order for \$30.00 plus \$4.50 shipping and handling, or call in your Visa or Mastercharge number to: WETA; Educational Activities; Box 2626; Washington, DC 20013. Tel. (800) 445-1964.

Planning, Conducting, and Evaluating Workshops, (1975), L. N. Davis, Austin, Texas: Learning Concepts, Inc. This is a practical guide for designing adult learning activities, such as conferences, seminars, and workshops. Starting with suggestions on how to assess personnel needs, the author guides the workshop planners through the steps of stating objectives, selecting resources, budgeting, and making arrangements. Several methods are provided for evaluating workshops. Sample forms are provided, as well as an extensive bibliography for further study.

Metropolitan Council DD Program
Mears Park Centre
230 East Fifth Street
St. Paul, MN 55101

If you no longer wish to receive this newsletter, please call (612) 291-6364, or write to the DD Program, Metropolitan Council Mears Park Centre, 230 East Fifth Street., St. Paul, MN 55101

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Editor: Kay Zwernik*

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1988 AGENDA: REALIZING THE VISION

Choicemaking: The Pathway to Independence

Think about all of the decisions we make in a single day, the choices we have control over: when to wake up, what order to get dressed in, what to eat for breakfast, and where to go for lunch. Then think about what it would be like if all of these decisions were made for us. For many persons with developmental disabilities the opportunity to make even the most basic decisions has not been permitted.

One of the most pervasive characteristics of developmental disabilities is that people who have them need significant assistance in all areas of daily living. Some parents as well as professionals have held the notion that severe cognitive or intellectual handicaps and/or the ability to communicate prevents people from consciously directing their own thoughts and actions. This is essential in being able to make choices. Because of this apparent inability, those who provide direct care have assumed that persons with severe disabilities are not capable of making choices or decisions that are in their best interests.

Research as well as our experience has shown us that people suffer harmful consequences when they do not have real and continuous opportunities to express preferences and to make choices. If a person is not affirmatively being taught how to make choices, communication can be severely stifled. Babies or young children may never achieve anything approaching communications potential. For persons who have acquired some communication skills during their lifetimes, they can often lose these skills.

For young and old alike, a "what's the use?" or "why bother?" feeling becomes the norm. People with severe cognitive and/or physical disabilities are particularly vulnerable to this. While it can be assumed that they need increased assistance to overcome their deficits and to learn to make choices, historically they have received little if any.

Several other things can occur when people are not given opportunities to exercise control over their lives. They may develop ways to receive attention such as maladaptive or self-injurious behavior. This behavior receives attention and is reinforced and this can begin a dangerous cycle.

People may also exhibit a learned helplessness which is commonly seen in public institutions and nursing homes. Passivity, negative tendencies, depression, low self-esteem, and a general lack of will to live are some effects of lost control over daily living activities.

It has been argued that people who have substantive intellectual and/or communication disorders plus a lack of experience in making choices cannot express themselves in a meaningful way when it comes to identifying their own needs, selecting services and expressing whether the services are actually helping them to grow and develop.

The act of developing and nurturing this skill in the person can by itself have a profound impact in parents' and providers' attitudes and expectations of the person. As family members, professionals, advocates or other concerned parties, it is our responsibility, as we have become more sophisticated over the years, to give the dignity of choice to persons with developmental disabilities. It is through repeated opportunities to make decisions that critical skills such as communication, social interaction and self-respect are acquired. All of these are

Activities, notices, services, products, etc. mentioned in this publication are for information purposes only and do not imply endorsement by the Development Disabilities Programs of the Metropolitan Council and the State Planning Agency.

essential for successful integration and maximizing independence.

Programs for persons with severe handicaps have historically been based on the attitude that professionals know exactly what is best for them. Thus highly structured programs have been developed to teach skills and behaviors. These have been very controlling and have diminished the ability of professionals to see people with severe handicaps as individuals capable of making choices or of even having the right to do so. It will, no doubt, be difficult for some professionals to relinquish this control in favor of teaching people to express their own preferences.

People with severe handicaps can learn to express their preferences and caregivers should be responsive to both typical and nontypical expressions of choice. In order to teach choice making, caregivers should hold three assumptions: 1) that all people have preferences, 2) that inner feelings of a person are expressed in outward behaviors, and 3) that there is a correlation between the level of interest and enjoyment, and certain outward behaviors.

Showing preferences involves three variables: 1). The tendency toward liking something; 2). One's choice or say about that something, and 3). A basic recognition that options do actually exist.

Up till now little attention has been paid to research on the topic of choicemaking or to developing instructional materials to assist instructors in creating environments and opportunities conducive to learning choice-making. One basic curriculum model, developed by Lucille A. Zeph, is called "Curriculum for a Humanistic Orientation toward Independence through Choicemaking Experiences" or C.H.O.I.C.E. It describes a four-step approach to teaching choice-making.

The first step involves exposure. The base of experience of an individual needs to be expanded, and this is accomplished by exposing them to new situations, places and people. Included could be parks, restaurants, tactile or sensory experiences, sounds, stores, foods, etc. Exposure to new things does not require that the person even be aware of where they are or whom they are with at the time. It is the repeated exposure to the new experiences that is important. People with even the most severe handicaps can participate in exposure experiences. Exposure to new situations and things builds a very basic foundation and provides the base for future choice-making.

The second step concerns awareness. Building upon situations to which they have been exposed, a person begins to make associations between the people, places and things. For example, a person may become aware that every time they go into a particular building, they eat ice cream. The person may become aware of the friendly hostess at the restaurant on Friday nights. At the awareness level a person may begin to categorize related

elements of an experience e.g., red building = ice cream or smile = dinner. Independent interactions of any kind are not required at this stage. Continued exposure will reinforce the awareness of the associations in their experiences and that is all that's required. Because of the associations the person may be able to express a preference if offered several possibilities.

The third step involves interactive experiences which require active participation on the part of the person with disabilities. For example, the person would order a food item or select a purchase. This step requires that the person interact with people and/or materials and actively choose between known options. Caregivers need to provide frequent opportunities in many situations to show preferences in order to build this skill.

The fourth step is mastery, when a person attains their own level of control and autonomy in a situation by incorporating and/or adapting earlier experiences into a current one. It involves being able to problem solve, request assistance, make new choices, initiate new action and adapt to situations. These skills are necessary if the goal is for people to live, work and play in socially and physically integrated community settings.

The Adult Services Committee of the Minnesota Association for Persons with Severe Handicaps has been working for several months to develop a resolution on choicemaking to present to the board. The writing of the resolution arose out of a deep commitment among the committee members that persons with severe developmental disabilities have the fundamental right to make choices for themselves and also the right to be taught how to make them. The resolution was approved at the July meeting of the MNASH Board of Directors and will be forwarded to TASH, the parent organization, for its consideration. Below is the approved resolution:

RESOLUTION ON MAKING CHOICES

Whereas, historically, many parents as well as professionals erroneously have thought that persons with severe cognitive or intellectual deficits or an inability to communicate verbally are unable to relate, compare, or consciously direct their own thoughts; and

Whereas, direct care providers have incorrectly assumed that persons with severe disabilities are not capable of making choices in their own best interests; and

Whereas, educational and instructional technology has been improperly based on models where care providers make determinations based on their own assumptions of what is in the best interest of the person with severe disabilities; and

Whereas, programming that minimizes initiative and spontaneity has been very controlling and does not permit even the most basic choice making; and

Whereas, active attempts by persons to deviate from the programs designed by caregivers have been interpreted as noncompliance, resulting in the establishment of behavior programs to decrease such presumably "maladaptive" behavior; and

Whereas, there is mounting evidence that the nature of environments and the competence of caregivers have been overriding factors influencing the ability and opportunity of individuals to make choices; and

Whereas, the assertion of making choices begins early in everyone's life; and

Whereas, it is assumed that all people have preferences, that inner feelings are reflected in outward behavior, and that there is a correlation between an individual's level of interest and enjoyment and their social behaviors; and

Whereas, choice making is an essential part of functioning independently as a member of society;

Be It Resolved that the Minnesota Association for Persons with Severe Handicaps:

Affirms the right of persons with severe developmental disabilities to express freedom of choice;

Supports research on methods that empower persons with disabilities to make choices in typical home and community environments;

Affirms the expectation that persons with severe developmental disabilities will be taught to make choices through exposure, awareness, interactive experience and mastery.

"ON THE JOB - HAVE YOU SEEN US?"

Editor's note: The following poem is written by Diane Bernin, who is a job coach for a public school system. She asked to share her thoughts, feelings, opinions, and what she goes through while carrying out the responsibilities of her position.

Have you met me before? Maybe you have.
I'm a Job Coach--so the title goes.
I take adults with disabilities into the real world
And try to teach them reality.
I do this on my own, yes I do.
I take them from a sheltered environment
and expose them to society.
When I take them into this "world"
I don't just go for walks
Although we do walk.

I don't just make small talk
Although we do talk--a lot.
I don't just play games and laugh
Although we manage to have fun.
I don't just "fill up" their days
Although the days never seem long enough.
I don't just expose them to people
Although we encounter many, many people.

No, I'm not just doing all that,
I'm doing a lot more.
I'm asking them to work in this real world.
I'm asking them to work hard
With no value of money,
With no set of consistent rules,
With no clear-cut reason why,
With no authority to back me up.

I'm asking them to work for the mere pleasure of working.
I am teaching them reality with the rules from another world.
I am telling them "you can survive in my world"
In this world--the "real" world--
When in actuality they can't.
They can't as long as I'm forced to treat them differently
because they are disabled,
and nondisabled people are afraid
to treat people with handicaps like all others.
We're afraid they'll break
or they'll crush
or that somehow they're not strong enough
to be treated with the same rules
as "normal" people are allowed to live by.

Somehow we must be gentler,
We must make exceptions,
We must shelter,
We must "take care" of them,
Because they are not capable of doing it on their own.

I am a Job Coach.
I take adults with disabilities into the "real" world
Where I ask them to work and I ask them to be
responsible.
I ask them to treat me as they would want to be treated.
I expect them to work and work hard.
I ask them to scrub floors and clean toilets.
I ask them to get on their knees and pick up garbage.
I ask them to stretch their muscles
More than they've ever been stretched before.
I ask all of this from them,
Then expect them to enjoy it.
I expect a good attitude,
And I expect them to be willing to do more
All of this without the value of money
Without the value of subsistence
Without the value of what the real world is really like.

I am a Job Coach.
I work with adults with disabilities.
Maybe that's true because nondisabled adults
Would never live by those rules,

Would never accept those conditions,
Would never allow themselves to be degraded and treated
As anything less than what their potential was really
capable of.

I am a Job Coach.

Have you met me before?

Maybe you have.

I'm the one with the adults with disabilities.

I'm the one trying to prepare them for a world no one
wants them in,

For a world they're not prepared for,

For a world they're expected to fit into.

FOR YOUR INFORMATION

Single Parent Support Group To Be Offered

A new support group for single parents who have children
ages birth-12 with disabilities will meet beginning
Tuesday, Oct. 4 from 6 to 8 p.m. at Courage Center in
Golden Valley. The group will meet weekly on Tuesday
evenings for eight weeks.

The group is designed to increase the knowledge, skills
and self-awareness of single parents to help them cope
and adapt to the social and emotional stresses of
parenting a child with a disability. Among the topics to be
covered are developing and using support systems;
managing time, stress and energy; balancing the needs
of all family members; emotional self-care skills; grief and
loss issues; and practical parenting skills.

To register for the group contact: Ann Dooley at 520-0436
by Sept. 20. Child care can be arranged. The group will
meet at Courage Center, 3915 Golden Valley Rd., Golden
Valley, MN 55442.

WORKSHOPS/CONFERENCES

September 10, 1988

"Your Family and You" is the topic of a presentation by
Elaine Hartsman, Ph.D, Licensed Consulting
Psychologist. She will talk about parenting and how
someone with a disability functions as an adult as a result
of that parenting. Rules of life, overprotection and risk
taking are some of the issues to be explored. The time is
10 a.m. to noon and the place is the United Way
Multi-Service Center, 14451 County Rd. 11, Burnsville,
MN.

September 14, 1988

"Coping in a Family with a Difference." Jim Kodadek,
director of counselling services at ARC Hennepin, will
discuss family relationships and how to deal with the
stresses involved in raising a child with a disability. The
time is 7 to 9 p.m. at the MN Bank of Cottage Grove, 7200
S. 80th St., Cottage Grove, MN.

September 27, 1988

George Borer, attorney, will talk about "Planning for the
Future: A Look at Wills and Trusts." He will suggest ways

families can develop an appropriate estate plan for their
children. Parents, regardless of their financial status, need
to consider how to divide assets among their children and
how to ensure that their son/daughter with a disability will
benefit from assets without endangering eligibility for
services such as Social Security or Medical Assistance.
He will speak from 7 to 9 p.m. at St. Stephens Lutheran
Church, 1575 Charlton St., West St. Paul, MN.

The above three programs are sponsored by the ARC
Suburban. Pre-registration is requested. Each program is
\$5 for members and \$10 for nonmembers. For more
information call: (612) 431-3700.

October 12-14, 1988

The Fifth Annual Colorado Statewide Vocational
Conference will be held at the Beaver Run Resort in
Breckenridge, Colorado. The theme is "Interdependence:
Creating Community Connections." Presentations will
focus on increased quality considerations in the
development of integrated options for people with
disabilities. For further information, contact: Cary Griffin,
Rocky Mountain Resource and Training Institute, 3805
Marshall St., Suite 202, Wheat Ridge, CO. (303) 420-4942.

September 16-17, 1988

"Community Referenced Behavior Management
Techniques" is a national conference that will focus on
strategies to support families and teachers. The strategies
to be presented are effective and can be administered by
local school and community personnel and families, and
are ethically acceptable for use within the community. It
is sponsored by the NIDRR Research and Training Center
on Community-Referenced Nonaversive Behavior
Management as a part of a five-year project to produce a
technology that utilizes the most advanced behavioral
theory available. Speakers will include Drs. Donald Baer,
Todd Risley, Tom Bellamy, Mark Durand, Gary LaVigna,
Laura Schreibman, Marjorie Charlop, Fredda Brown,
Richard Albin, Robert Horner, Jacki Anderson, Glen
Dunlap, Robert Koegel and Wayne Sailor. It will be held at
the University of California at Santa Barbara. The
registration fee is \$25. For further information contact:
Community-Referenced Behavior Management
Conference, Speech and Hearing Center, University of
California, Santa Barbara, CA 93106.

September 28-30, 1988

"Philosophy, Practice, Personhood: Achieving a Balance"
is the Third Annual National Community Integration
Forum which will address the importance of achieving a
balance in the three Ps. It will emphasize the importance
of support over systems, of choice over compliance, and
personhood over programs. The forum will be at the
Concourse Hotel and Governor's Club, One W. Dayton
St., Madison, WI. Registration fee is \$95. For more
information contact: New Concepts, 7425 University Ave.,
P.O. Box 376, Middleton, WI 53562.

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Minnesota State Planning Agency
Roger Strand, Editor
612/296-4018

Member of
National Association of
Developmental Disabilities
Councils

"ALL PERSONS WITH DEVELOPMENTAL DISABILITIES CAN BE SERVED IN THE COMMUNITY," DHS PROCLAIMS

On July 28, 1988, the Minnesota Department of Human Services (DHS) issued a document entitled, "Regional Treatment Center Negotiations Proposal," which stated, "All persons with mental retardation or related conditions can be served in the community. . . . It is time to identify the needed resources and plan for the placement of the remaining (1,494) persons into small, community-based homes."

The proposal is an attempt to clarify the role for the regional centers over the next 10 or more years, and presents a plan to complete the process of moving persons with developmental disabilities into small community-based homes while retaining a role for the state in the delivery of services. The proposal is based on a major premise that regional treatment centers could not be permanent homes, and therefore should provide specialized services designed to stabilize persons and promote their return to a small, community-based home, with their family, or in another placement.

DHS proposes to eliminate large state-operated congregate care of persons with developmental disabilities in the regional treatment centers by June 30, 1993. About 550 people, or one-third of the group in the regional centers would be served in state-operated homes for six people or less. The balance would be placed in other residences (non-state operated).

In addition, there are currently about 950 persons with developmental disabilities living in nursing homes. Under an agreement with the federal government, about 350 or these people must be relocated during the next year and a half.

Many resources will be needed to implement the plan:
--In-home support services, such as semi-independent living programs and the Family Subsidy Program, must be increased;
--More case managers will be needed and the procedures simplified;
--More staff will be needed at both state and county levels;
--Decisions will have to be made about alternative uses of buildings at regional centers;

--Technical assistance and training services will be needed;
--Regional center staff will be deployed and retrained.

For a complete copy of the proposal, contact: Developmental Disabilities Division; Department of Human Services; 444 Lafayette Road; St. Paul, MN 55155. Tel. (612) 297-1241.

FAMILIES GENERALLY SATISFIED WITH MOVE OF RELATIVES TO COMMUNITY SETTINGS, STUDY CONCLUDES

"On the average, family satisfaction with the services provided to their relatives increased after the person moved from a regional treatment center to the community," stated researchers in a recent Minnesota study. The survey report is entitled, A Survey of Family Satisfaction with Regional Treatment Centers and Community Services to Persons with Mental Retardation in Minnesota: Welsch v. Gardebring Class Members, (July, 1988). The report was written by Celia S. Feinstein, James A. Lemanowicz, and James W. Conroy of Conroy and Feinstein Associates (Philadelphia, Pennsylvania) in cooperation with the Office of the Monitor in St. Paul.

In June 1987, families of formerly institutionalized individuals with developmental disabilities participated in a sample survey. A questionnaire was mailed to the families of 164 persons who had been discharged from a regional center to a community placement during 1985 and 1986. There was a high participation rate, with 110 families (69.6 percent) returning the completed survey.

Findings in this study were very similar to comparable studies conducted in other states, such as: Connecticut, Texas, New York, Pennsylvania, and Nebraska. However, in other studies there was a pattern of initial opposition to community placement, including much stronger opposition among families of people perceived to be more seriously impaired.

The families in the Minnesota study indicated that they are now making more frequent visits than when their relatives were living in a regional treatment center. The average family member lived 55 miles from the regional center, and it took approximately one hour and 10 minutes to get there. "Currently, the average family lives 20 miles from the place where their relatives live and it takes 30 minutes to get there," the researchers concluded.

Copies of the complete report may be requested from:

STATE COUNCIL ON DEVELOPMENTAL DISABILITIES SEEKS NEW MEMBERS

Applications are now being accepted to fill anticipated vacancies on the Governor's Planning Council on Developmental Disabilities. **Applications are to be filed at the Office of the Secretary of State by December 1, 1988.** The Minnesota Governor's Planning Council on Developmental Disabilities represents a broadly based approach to planning and promoting coordination of services for persons with developmental disabilities. The Council assists in the development of a three-year plan and advises the Governor of Minnesota on policies pertaining to developmental disabilities.

People with "developmental disabilities" are those who have severe, chronic physical or mental disabilities, which appear before age twenty-two, and significantly limit a person's basic life functioning.

People who have a developmental disability are encouraged to participate on the Council. Other eligible applicants include: parents or guardians, providers of services, and people who have a special interest in developmental disabilities. People who live outside of the Twin City Metropolitan Area are especially encouraged to apply.

How to apply: Please contact the Secretary of State's Office to request the form entitled, "Application for Service in State Agency." Address: State Office Building, Room 180, St. Paul, Minnesota 55155. Telephone: (612) 296-3266.

ARC/US PREVENTION CURRICULUM FOCUSES ON PREGNANCY AND EFFECTS OF ALCOHOL

Teaching young people that pregnancy and alcohol don't mix is the goal of a new Association for Retarded Citizens (ARC) project on Fetal Alcohol Syndrome (FAS) and other Alcohol-Related Birth Defects (ARBD). A new curriculum has been produced by the Association for Retarded Citizens National Headquarters in Arlington, Texas for use in schools, church youth groups, seminars, civic groups, and other forums.

FAS and ARBD are being recognized as the largest single class of birth defects that are 100 percent preventable. While the full syndrome occurs in an estimated 1/750 live births, the incidence of babies born with some of these alcohol-related birth defects is said to be ten to twelve times that many. Among known alcohol-abusing women, however, FAS occurs in an astonishing 30 percent of those live births recorded. The annual cost, then, of

alcohol use during pregnancy is counted both in terms of thousands of lives affected by permanent birth defects and billions of dollars spent for health care, education, and lost productivity to society.

Some of the motivating beliefs behind this public education campaign are:

- that ARBD are a tragic waste of our most precious natural resource, our babies;
- that prevention of ARBD will not occur in the research lab, but in the community, utilizing information that is already available;
- that youth, tomorrow's parents, must be informed about the facts that will affect their children; and
- that our country's young people can make a big difference in educating and influencing for community change.

The following materials may be ordered through ARC of the United States, National Headquarters, P.O. Box 6109, Arlington, Texas 76005. Checks should be made payable to ARC of the United States.

- (20-4) Preventing Fetal Alcohol Syndrome and Other-Related Birth Defects (1988), a teacher's manual complete with lesson plans, masters for student text, transparency masters and student worksheets. (60 pages, \$5.00.)
- (20-5) Ten Projects for Preventing FAS and ARBD (1988), a manual for student involvement in community prevention activities. (24 pages, \$2.50.)
- (20-6) Have You Heard? (1988), a cartoon booklet teaching people about the prevention of FAS. (1-9 copies, \$2.00 each; 10-29 copies, \$1.00 each; Over 29 copies, \$0.50 each.)

MUAP ASSISTS LOCAL INTERAGENCY TRANSITION COMMITTEES

A statewide technical assistance project has been established by the Interagency Office on Transition of the Minnesota Department of Education at the Minnesota University Affiliated Program, University of Minnesota. The purpose of the project is to provide training, technical assistance, and consultation to the newly forming Community Transition Interagency Committees throughout the state.

In 1987, the Minnesota State Legislature passed legislation that required schools and community service agencies to form Community Transition Interagency Committees in order to encourage coordination, development, and improvement of transition services for

students with disabilities as they move from school to post-school work, living, and educational options.

To date, over 70 committees have been formed and are developing interagency agreements, identifying local resources, and developing written plans on how to best meet their students needs.

For information and assistance, call the Interagency Office on Transition (612) 296-0280, or Susan Ognanovich at the MUAP (612) 624-4848.

**NONAVERSIVE BEHAVIORAL
MANAGEMENT HOTLINE
AVAILABLE: 1 (800) 451-0608**

A new hotline for referral and assistance has been established at the National Research and Training Center on Community-Referenced Behavior Management at the University of Oregon. Special services are available by calling 1 (800) 451-0608 between 9:00 a.m. and 4:00 p.m. Pacific Time.

The purposes of the service are to: 1) refer individuals needing technical assistance with a severe behavior management problem to an identified consultant in the caller's region; 2) answer requests for information; and 3) refer requests for in-service to the training branch of the project.

PUBLICATIONS

Summary: McKnight Foundation. Minnesota Governor's Planning Council on Developmental Disabilities, 1988. This publication summarizes the results of projects funded under a grant from the McKnight Foundation to the Developmental Disabilities Program of the State Planning Agency. In December 1981, the McKnight Foundation awarded a grant of \$300,000 a year renewable for up to three years. This report covers projects that were funded during the second and third years of the grant in the following three areas: 1) training for staff and boards of agencies serving persons with developmental disabilities; 2) projects that would resolve or mitigate existing problems in delivery of services for persons with developmental disabilities but not mental retardation; and 3) projects that would resolve or mitigate existing problems in delivery of services for persons with developmental disabilities. Free copies are available by contacting: Governor's Planning Council on Developmental Disabilities; 300 Centennial Office Building; 658 Cedar Street; St. Paul, MN 55155. Tel. (612) 296-4018.

Minnesota Supported Employment Project: It's Working. St. Paul, 1988. This book summarizes the experiences during the first two years of a five year grant to the State of Minnesota from the Office of Special Education and Rehabilitative Services (OSERS) for the purpose of establishing the Minnesota Supported Employment Project (MnSEP). The emphasis of the grant was to involve the principal stakeholders in the process of system changes and to ease the transition to a new generation of services. The primary goal of MnSEP is to increase the quantity, quality, and diversity of supported employment opportunities for citizens of Minnesota who are challenged by severe disabilities.

One of the major activities was the funding of six start-up/change-over projects: Faribault Regional Center; Kaposia, Inc., St. Paul; United Developmental Achievement Center, Duluth; the St. Paul Rehabilitation Center; Alpha Developmental Achievement Center and Rathjen House, Hecla, Inc., Albert Lea; Northwest Supported Employment Initiative (a cooperative project of East Polk County DAC, Marshall County DAC, Clearwater County DAC, and the Polk County DAC). These projects were successful in placing over 140 people into supported employment positions in community work settings.

Also described in this publication are the other major activities of the project: research, technical assistance, training, and policy development. For free copies, please contact: MnSEP, 390 North Robert Street, 5th Floor, St. Paul, MN 55101. Tel. (612) 297-1873.

Publications: Minnesota Governor's Planning Council on Developmental Disabilities. July 1988. This brochure provides a complete listing of publications by the Minnesota Governor's Planning Council on Developmental Disabilities, such as: the policy analysis series related to the Welsch Consent Decree; the policy analysis series on issues related to Minnesota's state hospitals; briefing books for Minnesota policymakers; technology; demonstration grants; and quality assurance. A tear off order form is included. For a copy of the brochure, contact: Governor's Planning Council on Developmental Disabilities; 300 Centennial Office Building; 658 Cedar Street; St. Paul, MN 55155. Tel. (612) 296-4018.

Publication List: Association for Retarded Citizens of the United States. May 1988. This brochure lists available publications of the Association for Retarded Citizens of the United States along with an order blank. The publications are organized under the following categories: parents, prevention, community services, programmatic, organizational, employment, research, ARCFacts, and subscriptions. For a copy of the brochure, contact: ARC National Headquarters; P.O. Box 6109; Arlington, Texas 76005. Tel. (817) 640-0204.

The State Developmental Disabilities (DD) Program Office has acquired several education, training and resource materials. The following materials may be borrowed from the State Office only, located at the address on the front sheet of the State Supplement section of this newsletter. Tel. (612) 296-4018.

LENDING LIBRARY SELECTIONS

VIDEOTAPES AVAILABLE ON LOAN FROM THE GOVERNOR'S PLANNING COUNCIL ON DEVELOPMENTAL DISABILITIES

(Partial listing; VHS 1/2 inch):

- "Supported Employment--It's Working Out," Division of Rehabilitation Services, Minnesota Department of Jobs and Training, September 1986 (15 minutes).
- "Richard and Donna," (Topic: Supported Employment), Minnesota Supported Employment Project, Department of Jobs and Training.
- "Planning for Independence: Legal Alternatives to Conservatorship for Adults with Developmental Disabilities (in California)," Center for Public Interest Television, Hollywood, California, (45 minutes).
- "Peer Tutoring: Children Helping Children," Colorado Developmental Disabilities Council, (22 minutes).

- Productions by the Governor's Planning Council on Developmental Disabilities and the Minnesota University Affiliated Program (each on separate tapes):

"An Interview with Betty Hubbard, Past President of ARC Minnesota," (May, 1987).

"An Interview with Pat Juhrs (CSAAC, Maryland)," (Topic: Supported Employment for Adults with Autism).

"An Interview with Herb Lovett (Boston, Massachusetts)," (Topic: Positive Behavioral Management).

"An Interview with Toni Lippert," former planner with the Developmental Disabilities Program of the Metropolitan Council," (May, 1987).

"Breaking Down Barriers to Integration," presentation by Gunnar Dybwad, Ph.D., Professor Emeritus, Brandeis University, (February, 1987).

"International Disability Issues," presentation by Gunnar and Rosemary Dybwad, (February, 1987).

Metropolitan Council DD Program
Mears Park Centre
230 East Fifth Street
St. Paul, MN 55101

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INFORMATION EXCHANGE

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October 1988

1988 AGENDA: REALIZING THE VISION

More on Relationships

Building relationships and living in the community is a complex and challenging task for anyone. For a child or an adult with a developmental disability, this task is enormous. There seem to be so many barriers to overcome to develop the relationships upon which we all depend. These barriers include the segregated programs in which people with disabilities participate. Staff in special education classes, day programs, sheltered workshops, group homes and special recreation programs provide for their every need. There's no need to seek out the assistance of anyone else. Friendships with others outside really aren't encouraged or supported since it takes extra time and extra arranging.

The opportunity to develop and maintain relationships with nonhandicapped people is rarely present in our current service programs. As Jane Wells says in the videotape on Personal Futures Planning, "Most of us don't make a lot of friends at the post office." Normally people make friends in their neighborhood, at school or at work. Unfortunately too few individuals with developmental disabilities have any opportunities to meet nonhandicapped people in those environments.

A recent article in the newsletter of the Association for Persons with Severe Handicaps, written by Zana Marie Lutfiyya at the Center on Human Policy at Syracuse University, describes six characteristics she feels point out the differences between the ways typical people meet and develop relationships with others compared to people with disabilities.

Opportunity

Typical people can take advantage of numerous opportunities to meet and get to know other people. Opportunities for closer relationships are usually likely to occur around the neighborhood, at work, in clubs or associations, or at the church/synagogue. There are many opportunities to meet and get to know others even if they don't always become close relationships. Some examples are the grocery store, the library, service station, recreation center or beauty shop. With the tremendous mobility of people today, the opportunities abound.

For many people with disabilities, these opportunities may be almost completely lacking. While a person with a disability may be physically present, such as living in the community, there may be little interaction with neighbors or others in a group home. Toni Lippert in her book on case management, "The Case Management Team: Building Community Connections," describes this kind of community presence as "insulated." This means that learning occurs in separate, specialized locations such as a day program, special class or group home. Transportation barriers, rules and regulations, and numbers of people in one grouping are some of the circumstances that can prevent opportunities to develop relationships.

Support

People with disabilities have often not developed the skills to meet typical people and to develop relationships because they have had no experience in doing so. Once the opportunities are provided, it is important that adequate support be provided to foster the relationship. Lutfiyya provided an example in which support was needed:

Activities, notices, services, products, etc. mentioned in this publication are for information purposes only and do not imply endorsement by the Development Disabilities Programs of the Metropolitan Council and the State Planning Agency.

A woman wanted to go to church, something she had not done since she was a child. A church of the right denomination was located, the priest contacted, and a parishoner agreed to sit with Helen during mass and accompany her to the coffee hour afterwards. For Helen, this effort was not enough. She did not know how to behave in church and smoked cigarettes, talked and swore during the service. Not surprisingly, the parishoner became uncomfortable sitting next to Helen and soon stopped coming to pick her up. Helen needed to be with someone who could guide her appropriately while in church--someone who might suggest going out for a smoke, or sitting quietly until the service ended. Initially, a staff person sensitive both to Helen's need to attend church and the need for appropriate behavior might have made the difference by minimizing disruptions while allowing Helen to attend church and meet others in the congregation. This staff person could then have encouraged a member of the congregation to support Helen, in the hope that a friendship would develop.

Enhancing relationships between people with disabilities and typical citizens is not accomplished by throwing unsupported individuals together with unprepared companions. Not enough attention has been given to developing strategies for staff to use to assist people with disabilities as well as typical people in fostering relationships. More work needs to be done in developing strategies for initiating, developing and maintaining relationships. We need to identify what works and what does not work. Diversity

Most people with disabilities who have spent some or all of their lives in public institutions or community-based settings have had little variety in the people they interact with on a daily basis. Most are people paid to be with them. Paid people are, for the most part, in control of what the person with a disability does and with whom the person interacts.

As people with disabilities begin more and more to have the opportunity to meet other people and begin to develop relationships, it is imperative that caregivers give up some of their control. Control is in direct contradiction to the types of relationships we want to encourage them to develop. We must constantly pay attention to the differences between adequate support, guidance and protections, and over-protection that unnecessarily restricts a person in his or her movements and associations.

Continuity

Many of us thrive on oportunities to meet new and interesting people, but also are sustained by the long and continuous relationships we have had for many years. It is an important source of security and self-worth. Humans learn to trust others through long-term, stable relationships.

Many people with disabilities do not enjoy the same continuity in their relationships. Staff, case managers and

volunteers come and go, frequently causing a disruption to a person's life. Wolfensburger likened this to a "relationship circus" where staff and professionals dance in and out of a person's life, each in turn demanding instantaneous trust from the person with disabilities.

Service providers must learn to support long-term relationships through various types of assistance. Helping to send letters, dial the phone, remember occassions and going on a visit are some ways to help people with disabilities stay in touch with family and friends.

Freely given and chosen relationships

Others like and love us and choose to be with us because they want to, and we similarly choose to be with them. We accept and tolerate them and what they do and they do the same for us.

For people with disabilities this is rarely the situation. Most of the people in their relationship circle are paid to be with them. While some paid relationships are characterized by genuine warmth, caring and even love, often times relationships are restricted by schedules, regulations and pre-requisites.

Our goal must not simply be to introduce people to others, but to create an environment that will encourage typical members of our communities to voluntarily choose to form relationships with people whose lives have been marked by separation and loss. We have to look for people who have shown a special interest in the person with a disability and provide support to foster the relationship.

Intimacy

Intimacy as an expression of closeness, comfort and trust in other people is a way of sharing feelings and experiences. Most of us have a few people in our lives that we would consider "intimates" and we have chosen freely those people.

Many individuals with disabilities have no one with whom they share a close, intimate relationship. It is not easy to find ways to support intimate relationships between people with disabilities and their typical peers. It is important, however, and this is something we all strive to attain.

Conclusion

A mark of real acceptance of individuals with disabilities in our communities can be found in the relationships they enjoy with typical people. Although it may be difficult to create such relationships, the opportunities for people with disabilities to meet and interact with those without can be increased and encouraged. The fact remains that human service workers face the dilemma that they themselves may be barriers to the development of these desired relationships. (TASH Newsletter, September, 1988)

FOR YOUR INFORMATION

Supported Work Program Initiated for State of Minnesota Jobs

In 1987 M.S. 43A.421 was passed by the state legislature. This act created the Supported Work Program as part of a specialized program to provide employment opportunities throughout state government for people with severe physical, mental health and developmental disabilities.

Once the act was passed the Department of Employee Relations then had the task of working out a plan to implement it. A committee of all departments of state government was formed, and members began to investigate and wrestle with the many issues that arose. For example, one issue was trying to decide how benefits would be handled if three people were sharing one job. Issues like this took time to resolve, but the program is now operational and applications are being accepted.

The statute provides for 50 state jobs, and each full-time position may be shared by up to three persons and their job coach. It is expected that qualified applicants will seek work in the areas of manual labor, food service, laundry, janitorial/maintenance and general clerical.

To become a qualified applicant an individual must be referred by a Division of Rehabilitation Services counselor or a vendor such as a DAC or sheltered workshop. A "Certificate for Supported Work Alternative Testing Referral" completed by the above agencies accompanies the Application for Employment. The certificate is a statement of "readiness for work."

Supported workers differ from other state employees in three ways: 1) Supported workers are allowed to demonstrate their job competence through on-the-job trial work experience of up to 700 hours. This period replaces the competitive examination other employees take. The probationary period begins after the completion of the 700-hour qualifying period. 2) They work in close coordination with their job coach to ensure that the requirements of the position are met. 3) Supported workers are permitted to "share" their job with up to two other workers.

There are also things supported workers have in common with other state employees. They are paid the same hourly rate of pay as other employees, including the same eligibility for increases as other employees in the same class and bargaining unit. The benefits available to supported workers (such as life insurance, health coverage, vacation, sick leave, retirement and holiday pay) are the same as those available to other state employees. If their position is represented by a union, the supported worker is eligible to join the union and would then be responsible for paying union dues; they may choose to pay a "fair share" instead of joining a union.

Individuals may find out about available state positions by subscribing to the Minnesota Careers Opportunities Bulletin (MCOB). It is a bi-weekly publication and a subscription may be ordered from the Department of Administration Documents Division, 117 University Av., St. Paul, Mn 55155. The cost is \$20 for six months or \$25 for a full year. A check or money order must accompany the request.

People who have additional questions about the program may call Diane Pariana, who is coordinating the program, at (612) 297-2003.

David Hasbury at ARC Convention

At the state ARC convention in St. Cloud Aug. 19-20, David Hasbury from the Centre for Integrated Education in Toronto, Canada, gave a workshop for school personnel. The following two quotes from his presentation are provided below to serve as "food for thought."

*Segregated schools prepare people for institutions;
Segregated classrooms prepare people for group
homes or sheltered workshops
Integrated classrooms prepare people for living in the
community.*

* * *

*Isn't it wonderful that we are all different;
CELEBRATE that we are all different*

Consumer Case Management by Marijo McBride

The second year of the ARC Suburban Consumer Case Manager Program ended on Sept. 30, 1988. The program was funded by grants from the Governor's Planning Council on Developmental Disabilities, the Otto Bremer Foundation and its affiliate, Drovers First American Bank, the McKnight Foundation and the Nevin N. Husted Foundation.

In the first two years of the program 22 self advocates and parents were empowered by training, support, monitoring and a stipend in order to assume the role of consumer case manager for themselves or their children with developmental disabilities. As a result of the experience, one participant stated, "Through the consumer case manager program I have been able to do wonderful things like integrating my child in school."

A Consumer Case Manager Technical Advisory Committee and Task Force developed a number of different products such as a 1631 item multi-media library, a training package, an Individual Service Plan form and a strategy design for systems change guide necessary to implement a resource credit program.

Information regarding the Consumer Case Management Program and related program materials are available from: Marijo McBride, ARC Suburban, 14451 County Road 11, Burnsville, MN 55337; (612) 431-3700.

Overtime Work Available

Scott County's Human Services Department is seeking community volunteers to serve in the position of children's aide. The volunteers would work approximately three hours per week for a minimum period of six months. The children's aide provides a one-to-one relationship for recreational activities with a child who has a developmental disability. Orientation and training are provided. For more information call Laura Matuska, volunteer services coordinator, at (612) 937-6296 on M,T,TH,F.

WORKSHOPS/CONFERENCES

October 4, 1988

"A Parent and Professional's Perspective" is the topic of a speech to be given by Diane Crutcher, Executive Director of the National Down Syndrome Congress. She will talk about the impact of research in the area of Down Syndrome and mental retardation. The presentation will begin at 4:15 p.m. in Amundson Hall, Room B-75, which is on the corner of Washington and Church Sts, Minneapolis, on the University of Minnesota campus. The Institute for Disabilities Studies is sponsoring the presentation. There is no fee for attendance.

October 20, 1988

David Fassler, author and instructor in psychiatry at Harvard Medical School, will speak on "Changing Families: Children's Reactions to Divorce, Separation and Remarriage" at 7:30 p.m. at the Minneapolis Children's Medical Center, 2525 Chicago Av. S., Minneapolis. There is no fee for attendance. This speech is one of a series on psycho-social issues affecting children.

October 29, 1988

ARCs Suburban and St. Paul are hosting a presentation by Steven J. Taylor author and director of the Center on Human Policy at Syracuse University, Syracuse, N.Y. Dr. Taylor will speak on "Developing Community and Competence." He will focus on integration across the domains of home, community, leisure/recreation, and educational/vocational. The workshop will be at Drover's Inn, 701 S. Concord St., South St. Paul, from 8:30 a.m. to 3:30 p.m. The fee is \$25 for ARC members and \$30 for nonmembers, but scholarships are available. Lunch is included. For more information contact Lory Perryman, ARC Suburban, (612) 431-3700, or Jackle Stalley, ARC St. Paul, (612) 224-3301.

October 31 - November 1, 1988

"Innovation and Integration" is the title of a conference designed for community leaders in developmental disabilities and will feature speakers from throughout the country. Program sessions will emphasize how recent advances in basic and applied science research can change services and intervention approaches. The fee is \$225 and includes meals and entertainment. The conference will be at the Scanticon Executive Conference Center and Hotel, 3131 Campus Dr. Plymouth, MN. For

more information contact Sharon Vegoe, U of M Department of Professional Development, 107 Armory, 15 Church St. S.E., Minneapolis, MN 55455; (612) 625-3020.

November 11, 1988

"Meeting the Needs of Families...Developing Relationships" is the title of a day-long workshop for professionals who work with families in a variety of settings. T. Berry Brazelton will be the keynote speaker. Program topics will include families with a handicapped child, working families, parents who abuse and neglect children, stages of parenthood, teen parents and multi-cultural perspectives. Cost of the workshop is \$80. It will take place at the Sheraton Northwest in Brooklyn Park from 9:30 a.m. to 4:15 p.m. Registration is due by Oct 14. For more information contact Margie Thoreson, Minneapolis ECFE, Room 102, 1006 W. Lake St., Minneapolis, MN 55408; (612) 627-2927.

SPECIAL INVITATION

The Metropolitan Council Developmental Disabilities Program will begin the final year of its three-year project in case management. The third year will focus on the training of a select group of "Fellows" to be facilitators of Personal Futures Planning for families and individuals who have a developmental disability. You are invited to request an application from the DD program office by calling (612) 291-6364. From all applications received, a maximum of 15 will be selected to participate in this unique program, which will begin shortly after Oct. 1. Fellows will have a novel opportunity to interact with key national leaders in futures planning throughout the year plus receive a focused, values-based training in Personal Futures Planning from one of the leaders in futures planning, Beth Mount. This training will place new Minnesota leaders throughout the state to assist others in learning about and receiving futures planning. For more information about the Fellows program, call Kay Zwernik at the above phone number. This program will be funded by the Governor's Planning Council on Developmental Disabilities and will begin after a contract is signed. For more information on Personal Futures Planning, see the August, 1988 issue of this newsletter.

"SUCCESS STORIES" ADULT SERVICES QUESTIONNAIRE

THE ADULT SERVICES COMMITTEE OF THE MINNESOTA ASSOCIATION FOR PERSONS WITH SEVERE HANDICAPS (MNASH) IS SOLICITING THE ASSISTANCE OF NEWSLETTER READERS TO IDENTIFY EXAMPLES OF SUCCESS IN COMMUNITY AND SOCIAL INTEGRATION. THIS QUESTIONNAIRE IS DESIGNED TO GAIN INFORMATION ABOUT SPECIFIC INSTANCES OF EXTRA-ORDINARY SUCCESS REGARDING SERVICES FOR ADULTS WITH DEVELOPMENTAL DISABILITIES. EXAMPLES WOULD INCLUDE PERSONS LIVING AND/OR WORKING SUCCESSFULLY IN THE COMMUNITY, HAVING STRONG CONNECTIONS TO THEIR COMMUNITY, AND/OR GAINING IN INDEPENDENCE. ONE QUESTIONNAIRE SHOULD BE FILED OUT FOR EACH EXAMPLE. IF YOU HAVE SUCCESS STORIES TO SHARE, PLEASE FILL OUT AND RETURN TO:

KAY ZWERNIK
METROPOLITAN COUNCIL
MEARS PARK CENTRE, 230 E. 5TH ST.
ST. PAUL, MN 55101

1. FACILITY OR PROGRAM (IF APPLICABLE) _____

2. INDIVIDUAL FILLING OUT THIS QUESTIONNAIRE (NAME AND POSITION) _____

3. TIME FRAME OF INCIDENT DESCRIBED: FROM: _____
TO: _____

4. BRIEF DESCRIPTION OF PERSON(S) INVOLVED (EXCLUDE NAMES)

5. WHAT IS THE SPECIFIC INCIDENT OF SUCCESS IN HAVING THIS (THESE) INDIVIDUAL(S) GAIN IN INDEPENDENCE, BECOME CONNECTED TO THEIR COMMUNITY, BECOME INDEPENDENT IN COMMUNITY LIVING, SUCCEED ON THE JOB, ETC.?

6. WHERE WAS(WERE) THE INDIVIDUAL(S) LIVING AT THE TIME?

___ RTC ___ APARTMENT ___ PARENTS' HOME
___ GROUP HOME ___ FOSTER HOME ___ OTHER _____

7. WHERE WAS(WERE) THE INDIVIDUAL(S) WORKING?

- | | |
|---|---|
| <input type="checkbox"/> DAC | <input type="checkbox"/> ENCLAVE |
| <input type="checkbox"/> WAC | <input type="checkbox"/> SUPPORTED EMPLOYMENT |
| <input type="checkbox"/> SHELTERED WORKSHOP | <input type="checkbox"/> INDEPENDENT EMPLOYMENT |
| <input type="checkbox"/> OTHER _____ | |

8. WHAT WAS THE STAFFING SITUATION FOR THE SUCCESS INCIDENT? (I.E., HOW MANY STAFF, WHAT ROLES DID THEY PLAY, DID ONE PARTICULAR STAFF PERSON PLAY A SIGNIFICANT ROLE, ETC.)

9. HOW WOULD YOU DESCRIBE THE ATTITUDES OF THE STAFF INVOLVED IN THIS INCIDENT?

10. WHO ARE THE INDIVIDUAL'S FRIENDS, WHO ARE NOT PAID STAFF AND ARE NON-HANDICAPPED? HOW MANY FRIENDS ARE THERE? WHAT IS THE INDIVIDUAL'S SOCIAL NETWORK? WHAT WAS THE ROLE OF THE SOCIAL NETWORK IN THIS INCIDENT?

11. HOW WAS THE INDIVIDUAL ASSISTED IN BECOMING CONNECTED TO HIS/HER COMMUNITY? HOW WAS HE/SHE ASSISTED IN ESTABLISHING FRIENDSHIPS?

12. REGARDING THIS INCIDENT, IN WHAT CHOICES DID THE INDIVIDUAL PARTICIPATE?

13. WHAT PROBLEMS WRE IDENTIFIED? HOW WERE THESE PROBLEMS OVERCOME OR ADDRESSED?

14. IN YOUR VIEW, WHAT WERE THE KEY FACTORS INVOLVED IN THE REALIZATION OF THIS SUCCESSFUL OUTCOME?

INFORMATION EXCHANGE

STATE
SUPPLEMENT
October 1988

Developmental Disabilities Program
300 Centennial Office Building
658 Cedar St.
St. Paul, Minnesota 55155

Minnesota State Planning Agency
Roger Strand, Editor
612/296-4018

Member of
National Association of
Developmental Disabilities
Councils

GOVERNOR PERPICH ANNOUNCES A READY RESPONSE TO TECHNOLOGY ACT FOR INDIVIDUALS WITH DISABILITIES

On September 6, 1988, Governor Rudy Perpich announced that the Technology Related Assistance for Individuals with Disabilities Act of 1988 was signed by President Reagan on August 19, 1988. "The legislation," stated the Governor, "which was modeled after our Initiative on Technology for People with Disabilities, appropriates \$5.2 million for the coordination and delivery of technology and related services to people with disabilities." "Grants for this program will be awarded to states on a competitive basis," the Governor added.

The Governor has asked Rachel Wobschall and the Advisory Council on Technology for People with Disabilities to lead in the development of a comprehensive strategy and preparation of Minnesota's grant application. Perpich also requested cooperation and support from state offices in the process so that Minnesota can further the commitment of providing technology to Minnesotans with disabilities.

This new federal program under Title I of the Act is intended to provide assistive technology devices and services to individual of all ages with disabilities to enable them to lead more productive lives. Title I of the Act establishes a competitive state grant program to assist states to develop and implement consumer-responsive statewide technology related assistance programs. States can use the grant monies to fund model delivery systems, information-dissemination programs, training and technical assistance to individuals with disabilities and their families, employers, service providers and others, and also perform statewide needs assessments. Up to ten states could receive grants on a competitive basis the first year, up to 20 additional states the second year, and the remaining states would be funded the third year.

Title II of the Act would fund model service delivery systems, a study on financing technology to be conducted by the National Council on the Handicapped, a National Information Program Referral Network (providing a preliminary feasibility study results in a recommendation to fund such a network), and training and public awareness grants.

For a more complete summary of the Act, please refer to the August 1988 edition of Information Exchange--State Supplement, page 5.

Comments, suggestions, and questions concerning this program may be directed to: Rachel Wobschall, Director; Governor's Initiative on Technology for People with Disabilities; Department of Trade and Economic Development; Office of Science and Technology; 900 American Center Building; 150 East Kellogg Boulevard; St. Paul, MN 55101-1421. Telephone: (612) 297-1554.

DHHS ISSUES REQUEST FOR APPLICATIONS

On August 31, 1988, the Department of Health and Human Services in Washington, DC, announced in the Federal Register (Volume 53, Number 169) the availability of funds under the Fiscal Year 1989 Coordinated Discretionary Funds Program and requested applications for a variety of priority areas. Several areas for funding that are listed relate to developmental disabilities:

1. Collaborative training efforts to support children with more severe handicaps in Head Start;
2. Early intervention;
3. Family support practices;
5. Technical assistance projects to assist state planning councils, university affiliated programs, and state protection and advocacy system;
6. Community integration;
7. Adoptive parent groups--partners in the adoption of children with special needs;
8. Special needs adoption services and the mental health system;
9. Collaboration among adoption, mental health, and developmental disabilities service systems.

Technical assistance workshops will be held throughout the country--the closest one will be held in Chicago on October 2-5, 1988. Contact: Hich Yamagata at (312) 353-8322. The application forms and instructions are contained in the Federal Register, as listed above. Application deadline is November 10, 1988.

MENTAL RETARDATION POPULATION IN PUBLIC RESIDENTIAL FACILITIES DECLINES BELOW 100,000

New data published on public residential facilities by the National Association of Superintendents of Public Residential Facilities for the Mentally Retarded (NASPRFMR) indicates that the average daily population in public residential facilities has declined below 100,000, for the first time in many decades. New data are now available as a result of a study conducted by Richard Scheerenberger, Director of the Central Wisconsin Center for Persons with Developmental Disabilities. The report is entitled Public Residential Services for the Mentally Retarded, FY 1986-87.

Of the 274 public residential facilities (PRFs), 21 either closed during the fiscal year 1986-87 or were scheduled for closure by 1992. While total PRF capacity was reported to be 101,760 (down from 167,000 in fiscal year 1975-76), the actual population on June 30, 1987, was 93,172 and the average daily population was 91,479. The vast majority of residents of PRFs had profound (62.2 percent) or severe (20.8 percent) mental retardation. These figures indicated a substantial shift in the ratio of persons with severe-profound mental retardation in PRFs since fiscal year 1975-76, when the proportions were 44 percent (profound) and 29.9 percent (severe). The distribution according to chronological age also has substantially shifted; in fiscal year 1975-76, 63.4 percent of the residents were age 22 or older, while in fiscal year 1986-87, 86.4 percent of the residents were age 22 or older. The average per diem cost of care in fiscal year 1986-87 in PRFs was \$148.13.

The study contains several charts comparing national data by regions, chronological age, costs, and many other factors. The study also contains a chart for each state comparing basic data for the past decade.

Scheerenberger concluded in his discussion of the survey results: "In terms of future projections, it is apparent that residential populations, at least those in PRFs, will continue to decrease as a result of fewer admissions and readmissions, alternative placements, and deaths. Given these circumstances, with no major disruptions in current patterns, in 20 or 30 years the need for PRFs will be quite limited."

Copies of the report can be ordered for \$25.00 each from: Richard Scheerenberger, Ph.D., Director; Central Wisconsin Center for People with Developmental Disabilities; 317 Knutson Drive; Madison, WI 53704-1197.

PILOT PARENT NETWORK EXPANDS

Pilot Parents of Minnesota has been granted funds to develop peer support networks in the Northwestern and Southeastern regions of the state. This program provides one-to-one emotional support and basic information to parents whose sons and daughters have special medical, developmental, physical, or educational needs. Parents

who have their own experience are trained to offer assistance to others in their own communities.

The Northwest Minnesota Initiative Fund has awarded monies for Pilot Parent development in that region. The counties included are Kittson, Roseau, Lake of the Woods, Marshall, Beltrami, Pennington, Red Lake, Polk, Norman, Mahnomen, Clearwater, and Hubbard.

Funds for parent support activities in the Southeast are being provided by the Southeastern Minnesota Initiative Fund. Counties affected by this grant include Blue Earth, Brown, Dodge, Faribault, Fillmore, Freeborn, Goodhue, Houston, Le Sueur, Marion, Mower, Nicollet, Olmsted, Rice, Sibley, Steele, Wabasha, Waseca, Watonwan, and Winona.

Pilot Parents of Minnesota is a cooperative effort of the Association for Retarded Citizens of Minnesota, March of Dimes, Minnesota Association for Persons with Severe Handicaps, and the Minnesota Foundation for Better Hearing and Speech. Additional support has been provided by the Bremer Foundation.

Parents, advocates, and professionals interested in more information about pilot parents are encouraged to contact Lynne Frigaard, Pilot Parents of Minnesota, 201 Ordean Building, Duluth, MN 55802. Tel. (218) 726-4745.

MINNESOTA UAP TO PROVIDE TECHNICAL ASSISTANCE REGARDING CHILDREN WHO ARE BLIND AND DEAF

The Minnesota University Affiliated Program (MUAP) is currently involved in a cooperative project with the Minnesota Department of Education to provide educational services to children, youth, and young adults with deafness and blindness in Minnesota. The purposes of the Minnesota Deaf-Blindness Technical Assistance Project are to improve the lives of individuals through the provision of training and educational services to professionals and paraprofessionals as well as direct educational and rehabilitation services to both individuals who are deaf and blind and to their families.

This project started in October 1986 when the Minnesota Department of Education received a federal grant to provide educational services to children, youth, and young adults with deafness and blindness. Although all children with deafness and blindness are eligible for services through this project, two major thrusts of the grant have been identified: 1) to provide educational services for infants and toddlers who have deafness and blindness; and 2) to provide transition services for youth with deafness and blindness from secondary special education programs to post-secondary employment and community living. In September of 1987, a subcontract was developed with the Minnesota University Affiliated Program to carry out the majority of grant activities. For more information, contact: Kathy Steffens, Project Director; Minnesota University Affiliated Program; 6

Pattee Hall; 150 Pillsbury Drive, SE; Minneapolis, MN 55455. Tel. (612) 627-4616.

AIDS/DEVELOPMENTAL DISABILITIES CONNECTION EXAMINED

"Children with congenital AIDS usually have central nervous system dysfunction and a developmental disability," according to a recent "Prevention Update" issued by the American Association of University Affiliated Programs. The report entitled, AIDS and Developmental Disabilities, was written by Gary W. Diamond and Herbert J. Cohen of the Rose F. Kennedy Center University Affiliated Facility in Bronx, New York.

The authors stated that the number of pediatric AIDS cases reached approximately 563 in August, 1987, with an additional 1,600 cases of AIDS Related Complex (ARC). The numbers are increasing rapidly, they noted, with an additional 400 children expected to be born in New York City in 1988 with symptoms of Human Immunodeficiency Virus (HIV) infection.

Based on current projections, Diamond and Cohen believe that HIV infection may, in the next five years, become the largest infectious cause of mental retardation and brain damage in children. By 1991, the total number of children under age 13 with symptoms of HIV infection could reach 20,000.

Central nervous system involvement is a prominent clinical finding in infants and children with AIDS and ARC. Central nervous system involvement is estimated to be present in 78 to 93 percent of these pediatric cases, far exceeding the figure for adults, which is between 30 and 60 percent.

The clinical course of AIDS differs in children compared to adults. Most children with HIV infection acquired it prior to birth. Developmental delays are more prevalent in children with AIDS than with ARC, and often precede evidence of significant mental retardation. Citing a study of 68 pediatric AIDS and ARC patients, Diamond and Cohen reported that 10 percent had mental retardation and 7 percent were normal. Thus, they concluded, the short term prognosis for children with AIDS/ARC is relatively good; several children with HIV infection are now eight years old. "With an increasing number of such children being born and surviving for longer periods, a significant number of them will require developmental assessments and a variety of interventions," the authors stated.

Addressing concerns raised by family members and service providers, the authors said that the risk of transmission of the infection to health care workers is negligible. There has been no documented case of the spread of HIV infection to family members living with an infected person, except through sexual contact. Unless there is a flagrant contact with blood or a blood product, there is no significant risk of transmission. In addition, biting by an infected individual has not been

demonstrated to cause the spread of AIDS; nor have insect bites.

Finally, the authors write that the disease is preventable. In addition to educating women of child bearing age to avoid sexual contact with infected individuals and abstain from the use of intravenous drugs, they believe that children should be educated in the causes and prevention of the disease.

For additional information, write: Herbert J. Cohen, M.D., Rose F. Kennedy Center University Affiliated Facility, Albert Einstein College of Medicine, 1410 Pelham Parkway South, Bronx, New York 10461.

(Source: New Directions, (June 1988), National Association of State Mental Retardation Program Directors, Alexandria, Virginia.)

RESOURCES

* **University Film and Video Rental Service.** A number of films and video tapes relating to disabilities are available at a reasonable rental rate from the University of Minnesota Film and Video. Items may be used up to five days at a time. A listing of selections may be requested by contacting: University Film and Video; 1313 Fifth Street, SE, Suite 108; Minneapolis, MN 55414. Telephone: (612) 627-4270, Twin City Area; (800) 542-0013, Minnesota only; (800) 847-8251, Out-of-State.

* **Nonaversive Behavioral Management Hotline.** A new hotline for referral and assistance has been established at the National Research and Training Center on Community-Referenced Behavior Management at the University of Oregon. The purposes of the service are to: 1) refer individuals needing technical assistance with a severe behavior management problem to an identified consultant in the caller's region; 2) answer requests for information; and 3) refer requests for in-service to the training branch of the project. Special services are available by calling 1 (800) 451-0608.

CONFERENCES/WORKSHOPS

October 6, 1988 (7:00 to 9:00 p.m.)

"Fresh Winds for Sagging Sails" is a workshop featuring Heather McKenzie who will provide practical suggestions for caregivers. The workshop will be held at the Radisson Hotel South in Bloomington. For further information, contact: Wilder Foundation at (612) 642-4060.

November 3 and 4, 1988

"Empowerment in Deafness: A Tool for Growth" is the theme of the fall conference sponsored by the Minnesota Chapter American Deafness and Rehabilitation Association. The conference will feature Nancy Bloch of Gallaudet University and will be held at the Sheraton Midway in St. Paul. For more information, contact: Peg Killen (612) 770-5216 (voice), or Kristen Swan (612) 290-2524 (voice), or (612) 290-9062 (TDD).

The State Developmental Disabilities (DD) Program Office has acquired several education, training and resource materials. The following materials may be borrowed from the State Office only, located at the address on the next sheet of the State Supplement section of this newsletter. Tel. (612) 296-4018.

LENDING LIBRARY SELECTIONS

NOTICE: People who have materials out on loan that are overdue, please return them as soon as possible. There is often a waiting list of people who wish to borrow these materials.

Behavioral Weight Reduction Program for Mentally Handicapped Persons: A Self-Control Approach, Anthony F. Rotatori and Robert Fox, University Park Press, 1981. This book offers a behavioral program that observes and records behavior and proceeds on the basis of the data collected. The first part of the book provides the reader with some of the available knowledge concerning obesity. The second and major portion of this book describes a treatment package designed specifically for treating weight problems in persons with mental retardation. As illustrated in the last chapter, significant results can be achieved. The reader is advised to read the entire book before attempting to implement this treatment program.

Getting Employed, Staying Employed: Job Development and Training for Persons with Severe Handicaps, C. S. Mccloughlin, J. Bradley Garner, and M. Callahan, Paul H. Brookes Publishing Company, 1987. This book reflects many philosophies and methods begun by Marc Gold regarding a different approach to providing real jobs for persons with developmental disabilities. This book describes the processes involved in employing systems by which employment personnel can develop jobs in integrated settings, and methods for facilitating these opportunities for persons labeled "severely handicapped." The authors generate enthusiasm about making a difference in the lives of people with disabilities--to offer someone the chance to work, and the opportunity to experience the dignity that can come from working

Metropolitan Council DD Program
Mears Park Centre
230 East Fifth Street
St. Paul, MN 55101

If you no longer wish to receive this newsletter, please call (612) 291-6364, or write to the DD Program, Metropolitan Council Mears Park Centre, 230 East Fifth Street., St. Paul, MN 55101

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INFORMATION EXCHANGE

*Published monthly by the Developmental Disabilities Program of the Metropolitan Council
Editor: Kay Zwernik*

**Metropolitan Council
Mears Park Centre
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**Vol. 13, No. 11
November 1988**

1988 AGENDA: REALIZING THE VISION

Kyle's Day at the Pool

Bringing Kyle to the public pool was not my idea of fun. First of all, he would have to be watched like a hawk in case he should have a seizure in the water. Then I would have to make sure he wouldn't pull out his gastrostomy tube or that some other child wouldn't. And most of all, he is such a curious child, he would explore the entire pool and its surroundings in approximately 20 minutes, and he would find the exit. I would spend the rest of the afternoon chasing him out of the parking lot and back into the pool. These were last year's attitudes. This year the 90 degree heat helped change my attitude a little, and Kyle helped change my attitude a lot.

My 13-year-old son, Kent, suggested one hot, hot afternoon that we should all go swimming at the public pool. My girls were quick to chime in that they thought it was a good idea. When I glanced at Kyle who was throwing the last record out of the stereo case, I decided it was four against one. Since I have always believed in democracy, I said we could go to the public pool.

Everyone zoomed off to their rooms to change clothes. I put on my swimsuit quickly, grabbed Kyle's suit out of his drawer, and ran downstairs to change him. He wasn't in the family room. I called him, and then I heard the familiar "SPLISH, SPLISH, SPLASH KER-SPLASH." I ran into the bathroom and debated about whether I should bother with his swim trunks or just leave him in his soaking wet shorts. Stacy, my 11-year-old, came in and volunteered to get Kyle ready while I cleaned up the bathroom. (Sometimes she can be quite generous that way, but she couldn't fool me. She was worried I would change my mind about going to the pool.)

Stacy exited the bathroom with Kyle while I proceeded to pull objects out of the toilet. It has always amazed me how Kyle refuses to pick up his toys and deposit them in his toy box. Instead, he insists in depositing them in any available toilet. I was wondering if my husband would get upset if we put an empty toilet in Kyle's room to replace his toy box when Stacy came in and said they were all ready to go.

We all jumped in the car, and we were off. The pool is about five miles from our house, and it only took us about 20 minutes to get there. We made good time that day (Kyle threw his sister's towel out of the window, so we had to go back and retrieve it.)

We arrived at the pool, and my three older children were out of the car and in the water before I even removed my seat belt. Kyle was all smiles and must have sensed the excitement in the air because he started giggling. He only cracked me in the head twice with his seat belt, so I knew he was in excellent spirits.

We got out of the car and walked into the wading pool area. Kyle jumped in and started splashing madly while I hurried to stuff silly putty in his ears to protect his P.E. tubes. We were the only ones there, and he was having a ball. I was wondering why I had always dreaded coming to the public pool when children began arriving, in droves.

Kyle always becomes "upset" when a lot of people are around. He usually tunes them out and draws into himself and goes off into never never land, or wherever it is he goes. A little boy with bright red hair and probably about five years old (he was the same size as Kyle anyway) went up to Kyle and said, "Hi My name is Dan. Do you want to play? I'll be your friend." Kyle reached out and gently touched his hair and looked into his face. He smiled, made a sound, grinned, looked at me, smiled some more, sat down and started splashing Dan wildly. Dan sat down and splashed Kyle back, laughing like crazy.

Activities, notices, services, products, etc. mentioned in this publication are for information purposes only and do not imply endorsement by the Development Disabilities Programs of the Metropolitan Council and the State Planning Agency.

Some other children came over and started splashing. Kyle checked out every child in the same manner he had checked out Dan. He actually was not only noticing other children but playing with them. He came over to me (I was letting him alone, observing from my dry ?? post on the edge of the pool) and took my hand and led me to each of the children individually. I suppose there were six or seven kids. I smiled and asked the kids their names and told them Kyle's. He hugged me and pulled me down for some sloppy kisses. He has always loved to give me "slippery" kisses on my face. Then he started laughing and splashing like mad with the other kids again, so I went back to my seat.

Soon the children invented a game called "Shark." Kyle was the shark, and he would chase them. It was wonderful. For the first time in Kyle's five years, he was no different than any other child. He was just a little boy having fun playing with other little boys and girls at the public pool on a hot July afternoon. I sat on the edge of the pool and blinked back the tears for the lost little boy who had finally been found. That afternoon I realized how important integration is, not only in an educational setting, but in any community setting.

I know a lot of folks were pretty touchy this past summer when you would mention the hot weather, but I am very grateful, because it gave Kyle the opportunity to teach me a valuable lesson. I need to stop just getting through one day at a time and start planning for Kyle's future. Thanks to Kyle, some innocent children and some hot weather, his future now looks a whole lot rosier. Kyle no longer has to be a sideline observer in life. He can now become an active participant.

Written and shared by Kyle's mother, Linda Horkheimer

(Editor's note: The above is a "success story." It's the story of one event on one afternoon in Kyle's life. This one event will have significant impact on their family, but it wasn't something that had to change the entire system in order to qualify as success. There are many similar stories in Minnesota. The Adult Services Committee of the Minnesota Association for Persons with Severe Handicaps encourages you to share a story with others. Thank you to Linda for sharing hers.

RUNNING FOR OFFICE

This year David Breem ran for a position on the city council in Salem, Ore. He didn't win—in fact, he came in third. What is so unique about David Breem? David has mental retardation and is the first person with mental retardation to run for office in Oregon and possibly in the entire United States. The Salem City Council presented him with the city of Salem's Human Rights Award for the volunteer contributions he has made. He sits on 10 committees in that city with interests from homelessness to airports.

After spending 10 years in a public institution and more time in five group homes, David now has his own

apartment where he says he takes his own bus, does his own budget with his own money, goes anywhere he wants to and does a lot of volunteer work. He prefers an apartment because he has more responsibility—which you don't get living in a group home.

David has an obvious interest in disability issues, which is a prime motivator in running for political office. His interests, however, are not limited to the area of disability. He sites homelessness, transportation, jobs, airport expansion and other services as significant areas of interest. As a member of People First, David continually encourages all people with any type of disability to get involved in politics. He feels this is important because more people in the community can be served and can find jobs, and it also serves the state. Someday David hopes to run for Congress. Way to go, David.

FOR YOUR INFORMATION

"It's Never Too Early, It's Never Too Late"

The videotape on Personal Futures Planning recently released by the DD Program of the Metropolitan Council has been well received. The Council Data Center reports numerous requests have been received. It also reports that a considerable number of people are failing to return the videotape as requested. When the Data Center mails out the video, it requests the tape be returned in eight days, since many people are on the waiting list to see it.

Because the return rate has been so poor, the Data Center will now sell the videotape instead of loaning it. Copies are being provided to the Minneapolis and St. Paul libraries and to all county libraries where the tape may be borrowed free of charge. The charge for the tape is \$12 which includes postage. Send a check made out to Metropolitan Council and mail it to: Data Center, Mears Park Centre, 230 E. Fifth St., St. Paul, MN 55101. For people in greater Minnesota, copies may still be obtained from the Governor's Planning Council on Developmental Disabilities at 612/296-4018.

Appointments Open at Department of Education

Concerned individuals are being sought by the Minnesota Department of Education to serve on a task force, committee or advisory group, all of which work to improve schools in Minnesota. The State Board of Education and the Minnesota Department of Education rely on the advice of 27 task forces and committees to help design programs and develop policies on a wide variety of educational issues. Included are licensures, curriculum, finance, the black learner, migrant education, American Indian education, special education, and education of students who are deaf and blind.

To apply for these positions individuals must submit an application. As vacancies open on these committees, and they frequently do, the applications are on file and are reviewed and appointments made. Appointees are

reimbursed for meals and travel expenses incurred for attending committee meetings. In some cases, appointees also receive a daily stipend. For more information about a particular advisory committee and an application, contact Linda Dahlen, Affirmative Action Officer, at 612/296-0342.

Speakers Bureau Available

The Association for Retarded Citizens Suburban has begun a volunteer speakers bureau. Individuals will speak at community organizations, schools or youth groups in the Dakota, Scott and south Washington county areas. The program will consist of the videotape, "A New Way of Thinking," and a presentation of general information on mental retardation. To schedule a speakers bureau presentation, or to borrow the video, contact the ARC Suburban at 612/431-3700.

PUBLICATIONS

Expanding Options for Older Adults with Developmental Disabilities, A Practical Guide to Achieving Community Access and Activities Handbook and Instructor's Guide. Marion Stroud, Ph.D., and Evelyn Sutton, M.A., Paul H. Brookes Publishing Co., 1988.

These publications are a guide for families and staff who care about persons who have in most cases spent their whole lives in institutions or isolated at home—never knowing the pleasures of community participation. Use of these books will help broaden the experiences, social interactions and growth opportunities for these individuals in their later years.

The first book, *Expanding Options*, provides an understanding of the aging process, the characteristics of older disabled people and strategies for successful community involvement. This comprehensive resource provides the basic information needed to begin preparing older adults for various kinds of community access.

The book reviews the normal aging process and the types of services are frequently used by older persons. Several chapters compare two studies of 150 and 1,700 older adults in two different states. They looked at cognitive development, social competence, physical condition and community access to services. One section deals with constructive, non-threatening techniques for preventing and handling maladaptive behaviors without depriving adults of their dignity. The final section covers meeting the unique needs of these individuals through the interdisciplinary process to find access to activities in the community.

The second book, *Activities Handbook*, is a hands-on manual that provides 64 task-analyzed activities which show how to begin training adults for community participation once their interests and needs have been identified. Examples of some of the skills for instruction included in the book are personal grooming, finding help when needed, eating at a restaurant, cleaning an

apartment and enjoying hobbies. The books can be obtained by prepaying \$24 for *Expanding Options* and \$26 for *Activities Handbook* to Paul H. Brookes Publishing Co.; P.O. Box 10624; Baltimore, MD 21285; or by calling toll-free (800) 638-3755. A copy of both books is also available from the Metro Council DD library for loan by calling (612) 291-6364.

Community Recreation and Persons with Disabilities; Strategies for Integration is written by Stuart J. Schielen and M. Tipton Ray of the University of Minnesota. The book is a complete and practical "how to" guide that moves recreation and special education beyond theory and into practice. It begins with a historical overview of community leisure services and provides a rationale for including persons with disabilities in these programs. An approach for setting the stage for integrated programs which is proactive rather than reactive is detailed. The flow is from an initial information gathering stage through evaluation and, if followed, should ensure successful programs.

Successful participation requires an analysis of the sites or environment and activities the person with a disability wants to access. This includes an ecological inventory or analysis. This helps identify areas where the person needs assistance or modifications in order to participate. Schielen and Ray provide a format for accomplishing this. A chapter by Dr. Richard S. Amado provides strategies and solutions to behavioral issues based on applied behavioral analysis for the problems that are typically faced in recreational programs.

The book provides step-by-step procedures and forms for evaluating programs and activities. Obstacles such as staffing, attitudes, and resources are discussed and solutions provided for overcoming both real and perceived barriers to integration services. Numerous resources are included. To order, send \$25.95 to: Paul H. Brookes Publishing Co., P.O. Box 10624, Baltimore, MD 21285. A copy is available from the DD Program library for loan by calling 612/291-6364.

Resource on Battered Women with Disabilities

The Disability Awareness Project of the Minnesota Coalition for Battered Women has two new resources available. *A Guide to Better Advocacy for Battered Women with Disabilities* is an illustrated reference manual that provides information and a glossary which will assist advocates in better helping women with their accessibility needs. A videotape, "Breaking Free," shows four women with disabilities who share their experience with domestic violence and tell how being disabled may have compounded their situation. The manual is \$35; the video with captioning is \$200 and without captioning is \$175. Make checks payable to Minnesota Coalition for Battered Women, Physicians Plaza #210, 570 Asbury St., St. Paul, MN 55104.

New Journal Available

Journal of the Multihandicapped Person is a new quarterly journal which publishes research and clinical reports from psychology, special education, rehabilitation, counseling, social work, psychiatry, nursing and rehabilitation medicine. Investigations utilizing group comparisons or single-case experimental designs are the primary focus. The intent is for the reader to easily understand what was done, how it was done and why a given method was selected. For a free examination copy write: Penum Publishing Co., Attention: Suzanne Goss, 233 Spring St., New York, NY 10013.

WORKSHOPS/CONFERENCES

November 5, 1988

"Toward Growth and Independence---Facing Some Difficult Issues" is the topic for the Family Forum to be sponsored by the ARC Hennepin County. Issues such as AIDS, sterilization, children's rights vs. parents' rights, peer relationships, sexual expression and independence challenges will be addressed. The forum will take place at the Ambassador Hotel, Hwys. 12 and 100 in St. Louis Park, MN. The registration fee including lunch is \$15 for ARC members and \$30 for nonmembers. Contact the ARC Hennepin at 612/874-6650 for a registration form.

November 15, 1988

"An Overview of Developmental Disabilities" is a two-hour inservice training to be presented by Eleanor Field. It will be held at the State Capitol Holiday Inn, I-94 and Marlon St. in St. Paul, and will begin at 10:00 a.m. Topics covered will include definitions, history, causes and learning characteristics. Principles of several current practices will be explained. These include criterion of ultimate functioning, partial participation normalization, and least restrictive environment. The registration fee is \$15 and may be mailed to: Thomas Allen, Inc., 1555 Livingston Av., Suite 100, West St. Paul, MN 55118, before November 12.

November 15, 1988

"Techniques for Improving Academic Achievement in Inner City Youth" is the topic of a speech to be given by R. Vance Hall, Ph.D at 4:00 p.m. in Burton Hall, University of Minnesota, Minneapolis campus, Room 123. The free presentation, sponsored by the Institute for Disability Studies, is open to the public. Dr. Hall is director of Juniper Garden Children's Project. This project was developed because it was recognized that if education was going to benefit the lives of inner city poor youth, it had to begin early, had to be supported by the community and had to involve the children's families. The three-pronged program has been very successful and has gained national recognition.

November 17, 1988

Technology for people with disabilities is the topic of a conference sponsored by the ARC St. Paul called "Tools for Life." The conference will be held from 6:30 to 9:30 p.m. at Merriam Park Community Center, 2000 St. Anthony Av.,

St. Paul. The featured speaker will be Rachel W. director of the Governor's Initiative on Technology for Persons with Disabilities. A variety of exhibitors demonstrate various adaptors that help people with disabilities at school, on the job and at home. Admission is free.

SPECIAL INVITATION

The Metropolitan Council Developmental Disabilities Program will begin the final year of its three-year project in case management. The third year will focus on the training of a select group of "Fellows" to be facilitators of Personal Futures Planning for families and individuals who have a developmental disability. You are invited to request an application from the DD program office by calling (612) 291-6364. From all applications received, a maximum of 15 will be selected to participate in this unique program, which will begin shortly after Oct. 1. Fellows will have a novel opportunity to interact with key national leaders in futures planning throughout the year plus receive a focused, values-based training in Personal Futures Planning from one of the leaders in futures planning, Beth Mount. This training will place new Minnesota leaders throughout the state to assist others in learning about and receiving futures planning. For more information about the Fellows program, call Kay Zwernik at the above phone number. This program will be funded by the Governor's Planning Council on Developmental Disabilities and will begin after a contract is signed. For more information on Personal Futures Planning, see the August, 1988 issue of this newsletter.

INFORMATION EXCHANGE

STATE
SUPPLEMENT
November 1988

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Member of
National Association of
Developmental Disabilities
Councils

CLASS ACTION SUIT FILED ON BEHALF OF PERSONS WITH DEVELOPMENTAL DISABILITIES RESIDING IN NURSING HOMES IN ILLINOIS

On March 23, 1988, the Association for Retarded Citizens of Illinois (ARC/I) and 16 individuals filed a statewide class action law suit in the United States Federal District Court on behalf of all persons with developmental disabilities living in nursing homes. According to Pat Wear, Editor of Options, September 1988 newsletter of the Developmental Disabilities Legal Action Project, ARC/I, "The decision to seek relief in the courts has arisen from years of frustration as Illinois has fallen dramatically in relation to other states in terms of commitment to providing for the needs of persons with mental retardation and other developmental disabilities."

The 16 individual plaintiffs are representative of the 3,200 individuals with developmental disabilities (ages 25 to 69) living in nursing homes in Illinois. "The great majority (90 percent)," Wear indicated, "have no medical needs sufficient to justify nursing home placement." Wear continued, "Plaintiff's experiences are varied but they have in common years spent without habilitation and years of separation from family and community resulting in physical and behavioral regression."

Five Illinois state agencies share responsibility for the placement and maintenance of individuals with developmental disabilities in nursing facilities. The defendants are the Departments of Public Aid, Mental Health/Developmental Disabilities, Public Health, Rehabilitation Services, and Aging.

The Complaint sets forth in particular the harmful conditions in the nursing facilities—dehumanizing and unsanitary physical environments, restraints, psychotropic medications, substandard physical care, lack of therapy and behavioral programs, idleness and regression. "Unlike previous institution cases," noted Wear, "where the question of adequacy of existing services could be raised and professional judgment as to the level of services could differ, in these nursing facilities, with rare exception, no one even pretends that any services are provided."

A recent review by the Health Care Financing Administration of 71 nursing facilities in Chicago serving persons with developmental disabilities indicated that 59 provided no developmental training at all," Wear noted.

The plaintiffs are seeking the following from the Court:

- Provide effective developmental services to each class member;
- Stop further admissions to inappropriate nursing facilities and/or stop any transfer of persons out of these facilities, unless it is to a less restrictive setting where appropriate developmental services can be provided;
- Establish the necessary alternative facilities and services in advance of any transfer;
- Establish, train, and equip a sufficient number of case management personnel to plan and manage on an individual basis rehabilitation plans and community placement;
- Provide necessary therapeutic and support services to protect individuals from harm and regression;
- Make available to each class member a friend-advocate.

Bruce Smyth, President of ARC/Illinois, commented, "The decision (to file this class action suit) was made out of a sense of overwhelming frustration with virtually all aspects of the service system in Illinois. Because no relief could be foreseen on any front, the Board felt compelled to turn to the courts."

For more information, contact: Developmental Disabilities Legal Action Project; ARC/Illinois; 700 South Federal Street, Suite 123; Chicago, IL 60605.

"CHANGE IS A TRANSITION TO BE MANAGED"

"Resistance to new ideas, or change, is natural, and comes out of human needs, vulnerability, and a fear of a loss of control," said Frederick P. Nader, who served as one of the keynote speakers at the Third Annual National Community Integration Forum held in Madison, Wisconsin (September 28-30, 1988). Nader is the president of the National Training Laboratory Institute for Applied Behavioral Science, an association of senior professionals in human relations, training, and organizational development. The title of his presentation was, "Organizational Development/Organizational Change: Keys to Survival and Growth."

"People resist change in an organization for several reasons, such as: 1) they see no advantage in it for themselves; 2) they think it might be bad for the organization; 3) they do not see it as needed or logical; 4) they feel that their standards or values are being violated; 5) the change is too much too soon or too little too late; or, 6) it means more work," Nader listed.

"The conditions must be right for supporting change," he continued. "These conditions include: 1) there should be a dissatisfaction with the status quo; 2) the plan for change must be logical and realistic (there must be clarity in purpose); 3) the proposed change must be seen as being good for the organization; 4) people must have input into the plan; 5) there must be trust in the manager; 6) the plan for change must be seen as being manageable; and 7) people in the organization must realize how they will benefit from the change."

Nader then provided some steps toward achieving sanity during the process of making changes in an organization: 1) anticipate the resistance (change always produces resistance); 2) recognize and label it as resistance (people's behavior does not always mean disloyalty or incompetence); 3) welcome, explore resistance, and try to align yourself with those who are resisting; and 4) try to find useful ways to benefit from the energy."

"Think of change as a transition to be managed," Nader continued. "In this sense, the term 'conflict resolution' becomes meaningless. What is needed to manage change are: 1) good interpersonal skills; 2) access to staff; 3) ability to manage conflict; 4) time and interest; and most of all 5) being perceived as trustworthy and competent by other people in the organization." Nader then concluded, "Remember that people withdraw in times of uncertainty, and that new behavior must be rewarded, mistakes expected, and that people need slack to learn new ways."

APPLICATIONS SOUGHT FOR PARTNERS IN POLICYMAKING

The Minnesota Governor's Planning Council on Developmental Disabilities is currently seeking applications for participation in the third year of Partners in Policymaking. This is a one-year leadership training program designed to give participants skills to improve the quality of life for people with developmental disabilities. The training is intended for interested young parents of individuals with developmental disabilities or people who have a disability. Expenses are paid for travel, lodging, meals, and respite care. Selection will be made based on the quality of the applications. Please direct requests for application forms to: David Honcox; Education and Training; University Technology Center; 1313 Fifth Street, SE, (Suite 303); P.O. Box 80; Minneapolis, MN 55414. Tel. (612) 627-4624.

PUBLICATIONS

Purposeful Integration...Inherently Equal: D. Biklen, S. Lehr, S. F. Searl, & S. J. Taylor, Center on Human Policy, Syracuse University, 1987. This manual was prepared for the Technical Assistance for Parent Programs (TAPP) Project. It describes why integration in the schools is important, what it means, and also provides summaries of model programs. The authors analyze common objections to integration and how parents can be involved in encouraging schools to work toward integration. The authors conclude, "Integration in the schools is just the beginning of full integration in society." For further information, contact: TAPP Project; 312 Stuart Street; Boston, Massachusetts 02116. Tel. (617) 482-2915.

Towards an Understanding of the Demand for Personal Assistance: Rutgers University-Bureau of Economic Research and the World Institute on Disability. This is a joint research report of the two organizations listed above. The report provides an analysis of the need for personal assistance by people with disabilities, people who are elderly, and others. The authors point out that more than 7.7 million people in the United States, or 3.3 percent of the general population require some help from another person to accomplish normal everyday tasks, such as, housework, meal preparation, getting around, getting in and out of bed, and help with personal needs. The report analyzes a number of variables such as types of services needed, health conditions, and sources of financial assistance. For more information, contact: World Institute on Disability; 1720 Oregon Street, Suite 4; Berkeley, CA 94703. Tel. (415) 486-8314.

Nursing Home Reform: Implications for Services to Persons with Developmental Disabilities, National Association of State Mental Retardation Program Directors, 1988. This report furnishes a comprehensive analysis of the Omnibus Budget Reconciliation Act of 1987 (OBRA-87; P.L. 100-203), and its impact on persons with developmental disabilities. The purpose of the report is not only to describe the provisions of the new law but to delineate the issues that will have to be confronted at the federal and state levels in order to implement these statutory requirements. Specific topics covered include: 1) the evolution of federal policy; 2) preventing inappropriate placements of persons with mental illness and persons with developmental disabilities in nursing homes; 3) alternative strategies for planning by the states; 4) responsibilities of the Secretary of Health and Human Services and the various ways in which federal policies implementing P.L. 100-203 are likely to influence how the states organize their efforts to comply with the applicable provisions of the new law. For information on how to purchase this publication, contact: National Association of State Mental Retardation Program Directors; 113 Oronoco Street; Alexandria, Virginia 22314. Tel. (703) 683-4202.

Handicapped Parking in Minnesota (1988) is a brochure published by the Minnesota State Council on Disability. This is a handy and complete description of the provisions

NEEDS ASSESSMENT SURVEY

TECHNOLOGY FOR PEOPLE WITH DISABILITIES

The Governor's Advisory Council on Technology for People with Disabilities is requesting your assistance. Please complete and mail this questionnaire **by December 1, 1988**. This needs assessment survey will be used in preparing a proposal for a federal grant under the new federal Technology-Related Assistance for Individuals with Disabilities Act of 1988. Minnesota will be competing with other states for a grant from OSERS.

DEFINITIONS:

- **Assistive Technology Device**--means any item, piece of equipment, or product system, whether acquired commercially off the shelf, modified, or customized, that is used to increase, maintain, or improve functional capabilities of individuals with disabilities. Examples of assistive technology devices would include such items as: computer access equipment, switches, positioning and mobility devices, or augmentative communication devices.
- **Assistive Technology Service**--means any service that directly assists an individual with a disability in the selection, acquisition, or use of an assistive technology device. Examples include: 1) evaluation of the needs of an individual; 2) purchasing, leasing, or facilitating the acquisition of assistive technology devices; 3) designing or customizing devices; or 4) coordinating such services.

1. Name: _____

Agency: _____

Address: _____

Telephone: (____) _____

2. What types of disabilities apply to you, your clients, or your family members?

<p>_____ Visual impairment</p> <p>_____ Physical disability</p> <p>_____ Hearing impairment</p> <p>_____ Mental retardation</p>	<p>_____ Speech impairment</p> <p>_____ Emotional impairment</p> <p>_____ Learning disability</p> <p>_____ Other</p> <p>(Specify): _____</p>
---	--

3. In what ways are you involved with persons with disabilities?

<p>_____ Consumer</p> <p>_____ Parent</p> <p>_____ Educator</p>	<p>_____ Therapist/practitioner</p> <p>_____ Case Manager</p> <p>_____ Other (Specify)</p>
---	--

4. If you represent an agency or organization, how many people with disabilities are served each year? _____
5. Could you, your family member, or the people you serve benefit from the use of assistive technology devices?
5. _____ YES _____ NO
- 5_a If "yes", and if you represent an agency or organization, how many people with disabilities that you serve could benefit from the use of assistive technology devices? 5_a _____
6. Do you, your family members, or people with disabilities you serve currently use assistive technology devices and related services?
6. _____ YES _____ NO
7. Do you know where to obtain information on assistive devices and services?
7. _____ YES _____ NO
8. Have you or your staff participated in any type of awareness activities (e.g. training) regarding assistive technology devices?
8. _____ YES _____ NO
9. Please describe any additional needs you have relating to assistive technology devices and services (e.g., funding, equipment demonstration, training, etc.).
-

Thank You For Your Assistance

Please Fold, Apply Stamp, And Send To Address Below

Place
Stamp
Here

**MINNESOTA GOVERNOR'S PLANNING COUNCIL
ON DEVELOPMENTAL DISABILITIES
300 Centennial Building
658 Cedar Street
St. Paul, Minnesota 55155**

under Minnesota laws which provide for more convenient parking for persons with disabilities. Besides giving some of the reasons behind the law, the brochure lists eligibility requirements, and how to apply. For free copies, contact: Minnesota State Council on Disability; 145 Metro Square Building; Seventh Place at Jackson Street; St. Paul, MN 55101. Tel. (612) 296-6785, or (800) 652-9747 toll free (voice and TDD).

Mapping the Future for Children with Special Needs (P.L. 99-457), Administration on Developmental Disabilities, 1988. This publication was developed by the American Association of University Affiliated Programs Early Intervention Consortium project. It is intended to address the needs of decision-makers involved in implementing the Education of All Handicapped Children Act Amendments of 1986 (P.L. 99-457, Part H). This law established a new federal discretionary program to help states plan and implement a comprehensive, coordinated interdisciplinary program of early intervention services for children from birth through age 2. This publication provides a practical outline for decisions that need to be made related to the law, and provides material on issues of specific decision-making concern, including the populations to be served, childfind efforts, family evaluations, services, funding, training, and administrative issues. For purchasing copies, contact: Iowa University Affiliated Facility; Division of Developmental Disabilities; the University of Iowa; Iowa City, Iowa 52242. Tel. (319) 353-6390.

NEWSPAPER ON AGING AVAILABLE

The bi-monthly newspaper of the American Society on Aging, The Aging Connection, is available to non-members subscribers for the first time. The paper offers coverage of current issues and controversies, with updates on policy, practice, research, and new products and designs. The newspaper is available for \$25.00 per year (six issues) or \$45.00 for two years. Contact: American Society on Aging; 833 Market Street, Suite 512; San Francisco, CA 94103. Tel. (415) 543-2617.

REGIONAL EARLY CHILDHOOD WORKSHOPS SCHEDULED

A full day workshop has been scheduled at 22 sites throughout the state (November 1988 through January 1989). The purpose of the workshop will be to create a vision of what people want for young children (birth to age 5). For information about schedules, locations, and registration, contact: Early Childhood Family Education; Minnesota Department of Education; 992 Capitol Square Building; 550 Cedar Street; St. Paul, MN 55101.

UCPA TELECONFERENCE SCHEDULE ANNOUNCED

The United Cerebral Palsy Association will be sponsoring monthly teleconferences for affiliate groups, which is a cost-effective method for transmitting information and training. Topics include: employment, family support,

early intervention, technology, accreditation, grant writing, and personal assistance services. Sessions are scheduled on the last Wednesday of each month (with the exception of December, June, and August) from 2:00 to 3:00 p.m., Eastern Time. Registration fee is \$55.00 per teleconference site, regardless of the number of participants at each site. Information packets on each topic will be available for those participating. For more information, contact: Jim Hollahan; United Cerebral Palsy Association; 1522 K Street, NW; Washington, DC 20005. Tel. (800) USA-5UCP, toll free.

CONFERENCES/WORKSHOPS

November 9-11, 1988

"Know the Facts--Shape the Future" is a training conference regarding compliance with new federal regulations affecting Intermediate Care Facilities for the Mentally Retarded (ICF/MR) and nursing homes. Experts from relevant state agencies, service providers, and advocacy organizations will review the issues and involve participants in developing local/state implementation strategies with special emphasis on persons with physical and sensory impairments. Contact: Allan I. Bergman, Deputy Director; Governmental Activities Office; United Cerebral Palsy Associations; 1522 K Street, NW; Washington, DC 10005. Tel. (800) USA-5UCP, toll free.

November 14, 1988 (7:30 a.m. to 12:15 p.m.)

Mediation in Education: Dispute Resolution Forum for Public Officials is a special training conference for administrators in educational settings on how to make effective use of mediation. It will be held at the Holiday Inn Town Square in St. Paul. Cosponsors include: Office of Dispute Resolution of the Minnesota State Planning Agency; Minnesota Department of Education; and the Minnesota State Bar Association. Contact: Roger Williams; State Planning Agency; 300 Centennial Office Building; 658 Cedar Street; St. Paul, MN 55155. Tel. (612) 296-2633.

Announcing a New Clearinghouse on Training Activities

Beginning with the next issue of this newsletter, we will begin highlighting upcoming training efforts in Minnesota in a new format. Events such as courses, seminars, conferences, and workshops, related to developmental disabilities. The purpose of this new format is to: 1) provide a central and consistent resource for persons to identify upcoming training opportunities; 2) assist in the coordination of training efforts among the various agencies involved in training; and, 3) provide a vehicle for coordinating both training and technical assistance efforts, particularly when out-of-state consultants are brought into Minnesota to provide assistance. We are asking for your assistance in contacting us when you are in the process of planning upcoming events so that we can share that information with others. Please contact Ralph McQuarter at (612) 296-2160 or write: Minnesota DHS, Division for Persons with Developmental Disabilities, 2nd Floor, 444 Lafayette Road, St. Paul, MN 55155-3821.

The State Developmental Disabilities (DD) Program Office has acquired several education, training and resource materials. The following materials may be borrowed from the State Office only, located at the address on the front sheet of the State Supplement section of this newsletter. Tel. (612) 296-4018.

LENDING LIBRARY SELECTIONS

Rethinking Architecture: Design Students and Physically Disabled People, Raymond Fifchez, University of California Press, Berkeley, 1987. This book, available in paperback, examines an innovative and provocative experiment in architectural education. In an effort to develop a curriculum that was sensitive to the needs and challenges of people with disabilities, the author brought individuals with disabilities into the studio classroom as design consultants. As observed by the author, "In the past twenty-five years people with disabilities have become among the most vocal groups to protest the ways in which our society has attempted to exclude them, and they have pointed to the architectural environment as the most obvious symbol of how people who are able-bodied handicap those with disabilities. By working side-by-side with the design consultants, the architectural students not only learned a valuable professional lesson about client accommodation but also a profound personal lesson about human vulnerability and humility."

School to Work Transition for Youth with Severe Disabilities, P. McCarthy, J. Everson, M. S. Moon, & J. M. Barcus, Virginia Commonwealth University, 1985. Several authors have contributed to this monograph which was intended for participants in a "train the trainer" course sponsored by the Project Transition into Employment (TIE) at the Virginia Commonwealth University. The ultimate goal of transition, portrayed by the authors, is an array of meaningful employment, residential, and community options for young adults with disabilities. It is the development of a process which assures a smooth transition without a gap in services after school. Both professionals and parents must redefine the roles and responsibilities of school and adult service providers while working cooperatively to enhance inter-agency collaboration.

**Metropolitan Council DD Program
Mears Park Centre
230 East Fifth Street
St. Paul, MN 55101**

If you no longer wish to receive this newsletter, please call (612) 291-6364, or write to the DD Program, Metropolitan Council Mears Park Centre, 230 East Fifth Street., St. Paul, MN 55101

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(TIME-DATED MATERIAL)

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Editor: Kay Zwernik*

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December 1988

**1988 AGENDA
REALIZING THE VISION**

Editor's followup: The story last month of Kyle at the pool has elicited many positive responses from the readers of this newsletter. Therefore, readers may be interested to know that as a result of this one afternoon's experience, Kyle's mother changed her opinions about integration. She saw the value of social experiences in typical situations for her son. Linda, Kyle's mother, asked her school district for an integrated kindergarten class for Kyle. The school district responded favorably, and Kyle attends, with the assistance of an aide, a regular kindergarten class. Linda reports that things have proceeded smoothly and that Kyle has benefitted a lot from his interactions with regular kids.

**"THE BIGGEST PROBLEM--IS IN
OTHER PEOPLE'S MIND"**

*My brother Bobby never listens when I talk,
Pays close attention though and watches like a hawk,
Took some time for my hands to learn the signs,
But now the two of us, we get along just fine.*

*Bobby's biggest problem is in other people's mind,
We do things we like to do, and have a great time,
Some kids stay away, but if they knew him they would find,
Bobby's biggest problem, really, is in other people's
mind.*

*I've known Rosa for a year or so by now,
We've been all around, I sometimes wonder how,
The doors and stairs give us trouble with her chair,
It may take longer, but we go everywhere.*

*Rosa's biggest problem is in other people's mind,
We go where we want to go and have a good time,
Since this city's builders didn't think when they designed,
Rosa's biggest problem, really, is in other people's mind.*

*Angie reads to me the poetry she loves,
Hands brush the pages with the gentleness of doves,
Sings me a song from the piano clear and strong,
She's never seen me, yet she's known me all along.*

*Angie's biggest problem is in other people's mind,
We go hiking, we go swimming, in the summer sunshine,
Anyone can see I'm lucky she's a friend of mine,
And that Angie's biggest problem is in other people's
mind.*

*Sometimes the biggest problem is in other people's
mind, Be exactly who you are, and you'll do just fine,
Things may look impossible, but try and you will find,
That the biggest problem, really, is in other people's,
other people's ????????*

Someday we will change those people's mind.

**By Don Haynie
Free to be a Family**

FOR YOUR INFORMATION

Certificate in Developmental Disabilities

A new curriculum program is being offered through the Minnesota University Affiliated Program at the University of Minnesota. It is a 16-credit sequence of coursework in interdisciplinary study of developmental disabilities. Unique to the course work development has been the collaboration of 11 different academic units at the

Activities, notices, services, products, etc. mentioned in this publication are for information purposes only and do not imply endorsement by the Development Disabilities Programs of the Metropolitan Council and the State Planning Agency.

University. Adaptive physical education and recreation, health and social work are among the departments that have contributed their expertise in defining the courses and bringing their particular perspectives to students.

Winter Quarter

*EPsy 8770, Intervention Strategies for Persons with Developmental Disabilities: Interdisciplinary Perspectives

Spring Quarter

*EPsy 8603, Services for Persons with Developmental Disabilities: Research and Policy Analysis

The format of the program is readings, lectures and panel discussions. In addition to the 16 credits of course work, students are required to complete an internship. When finished, students will obtain a Certificate of Interdisciplinary Studies in Developmental Disabilities. For more information on specific courses and an application, contact the MUAP at 612/624-4848.

RESOURCES

Specialized Toy Store

In New York City, there is a toy store which specializes entirely in items for children with special needs. Started by a group of pediatric occupational therapists, the store has products such as a rocking horse with safety straps, battery-operated toys, pegged puzzles, adapted switches and other specialized equipment. A catalog may be obtained by writing to: The Able Child, 154 Chambers St., New York, NY 10007.

CPR Videotape

A step-by-step instructional 90-minute videotape on CPR and emergency choking procedures for an infant, child and adult is now available. CPR and emergency choking procedures are demonstrated for each age group. Learning is done at the viewer's own pace. A review section at the end of the video emphasizes the differences between each age group. There is a section on problems associated with CPR and how to avoid them. Also, an "easy-to-follow" study guide is enclosed. The videotape sells for \$29.95 in both VHS and Beta formats. Please add \$2.50 for postage and handling. Order from: Double A Productions, Inc., 279 S. Beverly Dr., Suite 1139, Beverly Hills, CA 90212.

EMPLOYMENT OPPORTUNITY

Hearing-Impaired Program Advisor

This position exists to provide outreach, information and referral, technical assistance, training and consultation services to human service providers within the geographic area served by the Metro Regional Service Center for Hearing Impaired People. Must have advanced

skills with American Sign Language and understand the social, cultural, economic and special needs of people with hearing impairments. To obtain an application contact: Minnesota Department of Employee Relations, 520 Lafayette Rd., 3rd floor, St. Paul, MN 55155. 612/296-6700 (V) or 612/297-2003 (TDD).

CONFERENCES/WORKSHOPS

December 5

PACER Center and the Early Childhood Regional Coordinator, Region 11 (seven-county metro area) are cosponsoring a workshop for parents of infants, toddlers and pre-schoolers with special needs. The workshop will give parents an opportunity to meet other parents, hear how the system works, gain tips on how to get good services for your child, find out about assessment and the Individual Education Plan (IEP) and learn how to communicate with professionals. The workshop will be held on Dec. 5, 7-9 p.m., at the McRae Neighborhood Center, 906 East 47th St., Minneapolis, MN. There is no charge for the program. Call 612/827-2966 to register.

December 7 - "The National Perspective on Local Transit Issues--An Exchange of Ideas"

The Regional Transit Board 1988 Annual Transit Conference will be held at the Radisson University Hotel, 615 Washington Av. SE., in Minneapolis. An afternoon panel will discuss "Accessibility Challenges: Meeting the Needs." Heather Menninger, of Claremont, Calif., Park Woodworth, of Portland Ore., and Lyle Peterson, from New Jersey, will discuss their city and state programs in accessible transportation, followed by a four-person panel of local responders. The panel will be from 2:45 to 4:30 p.m. For further information: RTB, 230 E. Fifth St., seventh floor, St. Paul, MN 55101. 612/292-8789.

DD PROGRAM LIBRARY

The Developmental Disabilities Program Library of the Metropolitan Council has recently updated its listing of books and resource materials. One page, double sided, is included in this issue of the DD Information Exchange. Two more pages will be included in future issues. Readers should remove these sheets and keep in a separate place to use as a future resource. All materials may be borrowed for three weeks and must be picked up from the Metro Council and returned or mailed back to the same. The Metro Council DD Program can only loan materials to residents of the seven-county Metro Area. Other resources are available for Greater Minnesota from the Governor's Planning Council on Developmental Disabilities.

DEVELOPMENTAL DISABILITIES CURRICULUM LIBRARY RESOURCE MATERIALS

Updated November 1988

Albrecht, Karl, Ph.D., Successful Management by Objectives - An Action Manual.

Allen, JoBeth; Clark, Fran; Gallagher, Pat; Scofield, Faith, Classroom Strategies For Accommodating Exceptional Learners.

Anderson, D.J.; Lakin, K.C.; Bruininks, R.H.; and Hill, B.K., A National Study of Residential and Support Services for Elderly Persons with Mental Retardation.

Apolloni, Toni, Capuccilli, Joanna, and Cooke, Thomas, Toward Excellence: Achievements in Residential Services for Persons with Developmental Disabilities.

AAUAP/American Association of University Affiliated Programs-DD, Developmental Handicaps: Prevention and Treatment IV (12-87).

ARC/Minnesota. Shopping Cards.

ARC/Minnesota. Community Health Education Network Materials Lending Library catalog.

Baker, Bruce L.; Brightman, Alan J; Hinshaw, Stephen P., Toward Independent Living.

Barrett, John and Lavin, Don, The Industrial Work Model: A Guide for Developing Transitional and Supported Employment.

Beebe, Patricia Dobbe, Vocational Advocacy for Parents Training Manual.

Bellamy, Vocational Habilitation of Severely Retarded Adults.

Bellamy, G. Thomas; Rhodes, Larry E.; Mank, David M.; Albin, Joyce M., Supported Employment: A Community Implementation Guide.

Bender, Michael, Valletutti, Peter J; Teaching the Moderately and Severely Handicapped Vol. I. Behavior, Self-Care and Motor Skills.

--- Teaching the Moderately and Severely Handicapped, Vol. II - Communication, Socialization, Safety and Leisure Time Skills.

--- Teaching the Moderately and Severely Handicapped, Vol. III - Functional Academics for the Mildly and Moderately Handicapped.

Bernstein, Gail S.; Ziamik, Jon P.; Rudrud, Eric H.; Czajkowski, Laura A., Behavioral Habilitation through Proactive Programming. (1986).

Bigge, June L. with O'Donell, Patrick A., Teaching Individuals with Physical and Multiple Disabilities.

Bruininks, Robert H.; Hill, Bradley; Lakin, Charles; White Carolyn, Residential Services For Adults with Developmental Disabilities.

Cheever, Raymond C., editor, Accent on Living Buyer's Guide.

Conference Proceedings: Family Care of Developmentally Disabled Members.

DesJardins, Charlotte, How To Get Services by Being Assertive.

Evans, Ian M., and Meyer, Luanna H., An Educative Approach to Behavior Problems: A Practical Decision Model for Interventions with Severely Handicapped Learners (10-87).

Falvey, Mary A., Community-Based Curriculum: Instructional Strategies for Students with Severe Handicaps (10-87).

Falvey, Mary A., Instructional Strategies for Students with Severe Handicaps.

Flynn, Robert J. and Nitsch, Kathleen E., Normalization, Social Integration and Community Services.

Friedman, Paul R.; The Rights of Mentally Retarded Persons: An American Civil Liberties Union Handbook.

Gardner, James F., and Chapman, Michael S., Staff Development in Mental Retardation Services: A Practical Handbook (10-87).

Gardner, James F.; Long, Linda; Nichols, Roann, and Lagull, Diane M., Program Issues Developmental Disabilities - A Resource Manual for Surveyors and Reviewers.

Gillette Children's Hospital, Minnesota Physical Therapist and Occupational Therapist Directory for Young People with Disability.

Hill, Bradley K., and Bruininks, Robert H., Physical and Behavioral Characteristics and Maladaptive Behavior of Mentally Retarded People in Residential Facilities.

- Horner, Robert H.; Meyer, Luanna H.; Fredericks, H.D.; Fredericks, Bud, Education of Learners with Severe Handicaps: Exemplary Service Strategies. (1987)
- Human Services Research Institute, Family Care For Persons With Developmental Disabilities: A Growing Commitment.
- Humphries, Tom; Padden, Carol, and O'Rourke, Terrence J., A Basic Course in American Sign Language. (1981)
- Intelligent Consumer Electronics, Northfield, Mich., The Handicapped's Source: Catalog of Products and Services.
- Iowa Department of Public Instruction, Integration Strategies For Students with Moderate and Severe Handicaps.
- Kennedy, Evelyn S: Dressing With Pride. Vol. I.
- Kiernan, William E., Ph.D, Changing Trends in Employment of Adults With Severe Disability.
- Laird, Dugan, Approaches to Training and Development.
- Lakin, K. Charlie and Bruininks, Robert H., Strategies for Achieving Community Integration of Developmentally Disabled Citizens. (1987)
- Lakin, K. Charlie; Bruininks, Robert H., Occupational Stability of Direct-Care Staff of Residential Facilities for Mentally Retarded People.
- Legal Advocacy for Persons with Developmental Disabilities in Minnesota; An Advocate's Guide to Case Management Services in Minnesota.
- Mager, R., The Mager Library: Developing Attitudes Toward Learning: Measuring Instructional Intent: Preparing Instructional Objectives: Developing Vocational Instruction: Goal Analysis: Analyzing Performance Problems.
- Magic Valley Rehabilitation Services, Inc. Twin Falls, Idaho Activities of Daily Living Curriculum for Handicapped Adults.
- Maryland State Planning Council on Developmental Disabilities, A Reader's Guide for Parents of Children with Mental, Physical or Emotional Difficulties.
- Maryland State Planning Council on Developmental Disabilities, You Can Do It : A Guide to Maryland's Services For Young Adults With Developmental Disabilities. (2) (1987)
- Maryland Supported Employment Project, Supported Employment Conversion Planning Workbook.
- McClannahan, Claudia; Farnan, Sheila; Splett, Patricia, Feeding and Caring for Infants and Children With Special Needs. (2)
- McLaughlin, Caven S.; Garner, J. Bradley; Callahan, Michael, Getting Employed. Staying Employed: Job Development and Training for Persons With Severe Handicaps.
- Metro Council/Metro Health Planning Board Services For People With Developmental Disabilities: A Guide for Private Funders.
- Minnesota Council on Foundations, Guide to Minnesota Foundations and Corporate Giving Programs. (1983)
- Minnesota Dept. of Education, Minnesota Transition Training Manual.
- Minnesota Dept. of Energy and Economic Development, Corporation Division, A Guide to Starting a Business in Minnesota. (3)
- Minnesota Dept. of Public Welfare, Minnesota Model Standards: The Development, Testing and Evaluation of a Proactive Assurance Mechanism for Facilities for the Mentally Retarded - Final Report.
- Minnesota Governor's Planning Council on Developmental Disabilities Policy Analysis Series (Issues Related to the Welsch v Noot Consent Decree).
- Musselwhite, Caroline R.; St. Louis, Karen W., Communication Programming for the Severely Handicapped.
- National Association of Developmental Disabilities Council, Patterns for Advocacy: How Council on Developmental Disabilities Achieve Public Policy Goals. (1985)
- National Association of Rehabilitation Facilities, Employment Survey for Adults with Developmental Disabilities.
- Perske, Robert, Don't Stop the Music.
- Perske, Robert, and Smith, Judy, Beyond the Ordinary: The Preparation of Professionals to Educate Severely and Profoundly Handicapped Persons Toward the Development of Standards and Criteria. (1986)
- Perske, Robert; Clifton, Andrew; McLean, Barbara M., and Ishler Stein, Jean Mealtimes for Severely and Profoundly Handicapped Persons - New Concepts and Attitudes.
- Popovich, Dorothy, Effective Educational and Behavioral Programming for Severely and Profoundly Handicapped Students.
- Popovich, Dorothy and Laham, Sandra L., The Adaptive Behavior Curriculum. Vols. I. and II.

INFORMATION EXCHANGE

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December 1988

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St. Paul, Minnesota 55155

Minnesota State Planning Agency
Roger Strand, Editor
612/296-4018

Member of
National Association of
Developmental Disabilities
Councils

100TH CONGRESS ADJOURNS: BENEFITS TO PEOPLE WITH DISABILITIES ADVANCED

On October 24, 1988, the 100th Congress adjourned, leaving many unresolved issues for the 101st Congress to reconsider when it convenes January 3, 1989. However, according to the Washington Weekly Review, of the American Foundation for the Blind (November 1, 1988), there were, on the balance, significant advances made on behalf of people with disabilities during the last two years. Although not complete, the following alphabetized list of legislative subjects presents the accomplishments and unfinished business (as related to disability issues) by the 100th Congress.

AGING: Last December, the Older Americans Act (P.L. 100-175) was signed into law, extending this program for another four years. Although a limited form of home health care assistance was included in the Catastrophic Protection Act (P.L. 100-360), the long-term home-health care bill, offered by Rep. Claude Pepper (D-Fla.), as a self-financing provision of Medicare, was defeated in the House last June. Other bills providing incentives for home health care of family members who are elderly with disabilities failed even to get a hearing. Rep. Pepper has vowed to reintroduce his bill in January. Various bills to delay implementation of the Catastrophic legislation, or to make its coverage optional rather than mandatory, can be anticipated for reintroduction in January. Long-term care issues can also be anticipated next month.

APPROPRIATIONS: It took the October stock-market plunge one year ago to persuade Congressional leadership to get together with White House budgeteers (in the so-called "economic summit" meetings) over fiscal 1989 spending levels reflected in the regular appropriations bills. Once agreement was reached, the bills were signed into law with commendable regularity. Meanwhile, the public debt limit has been increased to \$2.35 trillion, mainly to accommodate the cumulative increase in defense spending over the past eight years.

CHILD CARE: Although several child care bills were introduced in response to the needs of families with both parents working outside the home, no reported legislation ever came to a vote. Last August, however, P.L. 100-403 was enacted extending temporary child care for the rapidly increasing number of HIV-positive infants abandoned in hospitals by new mothers who had been infected with AIDS.

CHILD WELFARE: In mid-October, the first major overhaul of the welfare system in 50 years was signed into law (P.L. 100-485), due largely to the persistence of Sen. Patrick Moynihan (D-N.Y.). States must set up education, training, and work programs for former AFDC recipients, most of whom are single parents, with Medicaid coverage, and free child care extended for a year after recipients work themselves off welfare. In addition, all states are required to include poor two-parent families under Medicaid coverage, thus increasing early medical intervention and treatment for families who cannot afford medical care.

DEAF: Due largely to heightened public concern for people with hearing impairments as a result of media coverage of Gallaudet student activism, there were four major pieces of legislation passed: 1) all new telephones made must be compatible with hearing aids (P.L. 100-394); 2) a new National Institute on Deafness will be established, included in the massive Public Health reauthorization bill, thanks to the efforts of Rep. Claude Pepper (D-Fla.); 3) the number of telephone devices for the deaf (TDD) will be greatly expanded within federal agencies; and 4) a bill was passed two days before adjournment that will provide for bilingual court interpreters for deaf litigants whose native language is not English.

DISABILITY: The passage of P.L. 100-407, Technology-Related Assistance for Individuals with Disabilities Act, was passed with swift Congressional consensus. (See Information Exchange—State Supplement, August and October 1988). An anticipated issue in January will be a renewed effort to provide medical and personal leave for employees with family members who have a disability or are ill.

DISCRIMINATION: The passage of the Civil Rights Restoration Act (P.L. 100-259) was one of the more dramatic instances for testing the balance of power among the three federal branches of government. It was introduced in 1987 to specifically overturn the Grove City Supreme Court decision. After passing overwhelmingly in January, it was vetoed by the President. With determined efforts of a nationwide coalition of disability advocacy groups, Congress overrode the veto in March. The Americans with Disabilities Act, sponsored by the National Council on the Handicapped, proposed to prohibit discrimination against people with disabilities in every activity of the federal, state, and local government. The Council has conceded to submit the bill's various

components into separate legislative packages during the next session.

EDUCATION: A five-year extension of elementary and secondary education assistance was signed into law in March 1988 (P.L. 100-297). Next year, committees will be turning their attention to extending discretionary programs under the eight-part Education for Handicapped Children Act (EHA). The Office of Education will be implementing the Technology-Related Assistance Act, as described above.

HEALTH: A massive Public Health Service bill (S. 2889), was approved by Congress in October, and at this writing is awaiting the President's signature. This bill reauthorizes certain National Institute on Health programs and all other PHS training and grant programs. It also establishes the National Institute for the Deaf, and authorizes \$1.5 billion for new research on AIDS.

HOUSING: P.L. 100-430, the Fair Housing Act, signed into law in early September 1988, requires incorporation of accessibility standards into all new multifamily housing units. Also passed in the closing hours was legislation extending housing, health, and social services to the homeless, which the President is expected to sign into law.

INTERNATIONAL: The revised international trade reform bill (after a presidential veto) was passed in August 1988. It contains a provision for permanently extending duty-free import of articles for people who are blind or have other handicaps.

LABOR: Efforts to increase the minimum wage level were unsuccessful, and this is expected to be reintroduced.

LEGAL SERVICES: For the first time in 8 years, the administration has softened its opposition to the Legal Services Corporation. Fiscal 1989 funding is \$308 million, included in the appropriations bill for State, Justice, and Commerce.

LOBBYING: Legislation introduced by Rep. J.J. Pickle (D-Texas) in 1987 to restrict any political activity by nonprofit organizations never progressed past the hearing stage.

MEDICARE: As mentioned under "Aging," above, the Catastrophic Protection Act will be subject to review hearings early in the next Congress, due to Medicare beneficiaries' widespread protest over its cost-benefit ratio. In another area, last-minute legislation was passed to strengthen regulatory review of clinical laboratories receiving Medicare or Medicaid funds, which will provide greater accuracy in lab tests.

MENTAL ILLNESS: Legislation (P.L. 100-509), was signed into law, which will extend and improve protection and advocacy programs for people with mental illness residing in institutions.

SHELTERED EMPLOYMENT: In extending programs under the Small Business Administration, Congress reauthorized a provision to allow rehabilitation facilities to bid on small business set-aside contracts and established five-year ceilings on these contracts.

TAXES: A one-year extension of the Targeted Jobs Tax Credit program was approved in the final version of the Technical and Miscellaneous Revenue Act. Also included was a tax exemption for the sale of a homeowner's (with a disability) residence after the owner moves into an institution.

TRANSPORTATION: On the day before adjournment, Congress decreed nationwide uniformity in handicapped symbols used to designate parking spaces intended for drivers with a disability and whose license plates carry the approved symbol.

PUBLIC HEARINGS SCHEDULED ON TECHNOLOGY FOR PERSONS WITH DISABILITIES

The Governor's Advisory Council on Technology for People with Disabilities will sponsor five public hearings in December and January. The purpose of the hearings will be to receive testimony regarding what possible barriers might exist that prevent people with disabilities from accessing technology-related services and devices. The Council would also like to learn about how technological devices have helped people to accomplish their goals and gain greater independence. People are encouraged to testify, in addition, as to how the Governor's Advisory Council can make technology more available to the citizens of Minnesota. This information will be collected to assist the Governor's Advisory Council in preparing a grant application under a newly created program administered by the U.S. Office of Education.

The public hearings will be held as follows:

DULUTH
Wednesday, Dec. 7, 1988
1:00-4:00 p.m.
Duluth Public Library
520 West Superior

ST. CLOUD
Thursday, Dec. 15, 1988
3:30-5:30 p.m.
The Americana Inn
Highway 10 South

ROCHESTER
Thursday, Dec. 15, 1988
5:00-7:00 p.m.
Newbridge Apartments
325 18th Avenue South

ST. PAUL
Friday, Dec. 16, 1988
10:00 a.m.-1:00 p.m.
Gillette Children's Hospital
200 East University Avenue

MOORHEAD
January 18, 1988
7:00-9:00 p.m.
Ballroom, Comstock Memorial Union
Moorhead State University

Please call (612) 297-1554 to register, and please indicate if an interpreter or other accommodations are needed. Testimony will be limited to five minutes per

person, and people are encouraged to submit their comments in writing if possible.

Those unable to attend may submit comments to: Governor's Advisory Council on Technology for People with Disabilities; Minnesota Department of Trade and Economic Development; Office of Science and Technology; 900 American Center Building; 150 East Kellogg Boulevard; St. Paul, MN 55101-1421.

NEW NATIONAL ASSOCIATION ON SUPPORTED EMPLOYMENT FORMED

A new national association is being formed to foster the growth and development of supported employment. The organization is called, the **Association for Persons in Supported Employment (APSE)**. The organization was initiated as a result of participants in supported employment (primarily front-line implementors) voicing a need for meaningful representation of their issues and concerns. The overwhelming consensus among people who are involved in supported employment is that this is an exciting and rewarding activity for both staff and the individuals who are becoming employed through supported employment services. It is anticipated that APSE will promote the use of supported employment and encourage widespread change at the system and policy levels. APSE is committed to improve the capacity to serve more individuals as well as to enhance the quality of supported employment services. For membership information, contact: Wendy Wood; APSE; P.O. Box 27523; Richmond, Virginia 23261-7523. Tel. (804) 266-6950.

MINNESOTA UAP TO DEVELOP TRANSITION FOLLOW-ALONG/FOLLOW-UP SYSTEM

The United States Department of Education has recently awarded one of four national grants to the Minnesota University Affiliated Program on Developmental Disabilities at the University of Minnesota to develop a Secondary Transition Follow-Along/Follow-Up System. The goal of the project will be to develop and provide an effective information system that will describe the post-school experiences of students with handicaps. Very few systems for following students through school and beyond currently exist. This demonstration project will:

1. establish a follow-up/follow-along monitoring system that reports on the post-school outcomes of special education graduates and on former students who failed to successfully complete their programs;
2. use information gained from the monitoring system to recommend and make programmatic improvements in all areas of assessment, curriculum, and program planning for transition;
3. use standardized measures of student academic, social, vocational, and adaptive behavior to produce a reliable and valid means of anticipating and

reporting on the post-school service needs of special education students;

4. design procedures to effectively analyze student characteristics and attributes, environmental conditions, and curriculum experiences that enhance or inhibit the successful transitions from school to employment and community living options;
5. develop systematic interagency strategies in the improvement of transition services; and
6. extensively evaluate, report, and disseminate the results of this project to a wide audience of professionals.

The project's activities will be implemented in three phases over the next four years. Procedural guides describing all components of the follow-along/follow-up system will be produced and disseminated at regional training workshops throughout Minnesota during the final phase of the project. For further information, contact: David R. Johnson, Minnesota UAP; 6 Pattee Hall; 150 Pillsbury Drive S.E.; Minneapolis, MN 55455. Tel. (612) 624-4848.

PUBLICATION

Guidelines on Developmental Services for Children and Adults with HIV Infection, (First Edition), A. C. Crocker, & H. J. Cohen, American Association of University Affiliated Programs, August 1988. These guidelines were prepared with the particular needs in mind of program administrators and workers in the field of developmental disabilities. This is to be considered as a "working document" that will be revised as more is learned about Acquired Immune Deficiency Syndrome (AIDS) and what is needed to bring about a systematic approach to providing services to this "new minority" segment of the population. "Indeed," write the authors, "it could be stated that young people with human immunodeficiency virus (HIV), compounded by a collection of segregating features, render them virtually an 'ultimate minority.' Isolating factors include their having (a) an uncommon disorder, (b) which is progressive and fatal, (c) and for which there is public fear of contagious spread, (d) plus frequent mental retardation or other developmental disability, (e) families in disarray, and (f) often racial or ethnic minority circumstances... It is hoped that the infectiousness issue can be seen at its more appropriate level of limited concern, and that developmental and child welfare services be carried out considerately." "The need for enhanced services seems evident, and the potential risk of viral transmission from client to worker, or client to client, is remote and manageable," state the authors. A copy of this publication may be requested from: American Association of University Affiliated Programs for Persons with Developmental Disabilities; 8605 Cameron Street, Suite 406; Silver Spring, Maryland 20910. Tel. (301) 588-8252.

The State Developmental Disabilities (DD) Program Office has acquired several education, training and resource materials. The following materials may be borrowed from the State Office only, located at the address on the front sheet of the State Supplement section of this newsletter. Tel. (612) 296-4018.

LENDING LIBRARY SELECTIONS

Design of High School Programs for Severely Handicapped Students, B. Wilcox and G. T. Bellamy, Paul H. Brooks Publishing Company, 1982. This text attempts to integrate current best practice and promising approaches in providing high school services for students with severe handicaps. Focus is on the preparation of students for functioning in future work and living environments and providing effective transition to those environments. Content includes: basis for program design, curriculum content, individualized education programs, community activities, instructional methods, vocational preparation, and preparing students for independent living, leisure and recreation. A special chapter addresses administrative concerns and the need for support services. An additional chapter addresses the need to facilitate the transition of students from school to adult life and adult services.

Living and Learning in the Least Restrictive Environment, R. H. Bruininks & C. Lakin, Paul H. Brooks Publishing Company, 1985. This book examines a range of topics relating to the origins, implications, and substance of important social changes in the past decade that have granted citizens with handicaps a fuller share of legal equality and social participation in society. Primary focus is on services for persons whose handicaps are so substantial that they are likely to require some degree of lifelong support. While recounting the many accomplishments of the past decade, this book also delineates the multitude of tasks left to be accomplished. The authors have intended to assist in making the state-of-the-practice equal to the state-of-the-art and, in the process, contribute to the future improvement of both.

**Metropolitan Council DD Program
Mears Park Centre
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St. Paul, MN 55101**

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