

# INFORMATION EXCHANGE



*Published monthly by the Developmental Disabilities Program of the Metropolitan Council*

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## METROPOLITAN COUNCIL DD PROGRAM NEWS

### 1987 AGENDA: INTEGRATION AND QUALITY

Two very clear themes will be emphasized in 1987 by local and national consumer advocacy and professional organizations. They are **community integration** and **quality services**. Neither is a new concern but each will be more pronounced in the year ahead. Because they will be so prominent at the local, state and federal levels, it is critical to accurately understand what these concepts mean as we try to help persons who are developmentally disabled achieve them.

This issue of the **DD Information Exchange** initiates the first in a series of articles which will follow in succeeding months. Explanations of key terms and concepts, relevant activities and suggestions for further reading will be included in this section and under the **FEDERAL HIGHLIGHT** section.

**Community Integration** is an idea to which the DD constituency has long subscribed, but thus far has failed to realize. To date, we have brought back or kept many people who are developmentally disabled in the community. They have community presence because they are visible and physically located in their communities. The agenda now is to assist them to achieve the "integration" phase. The Minnesota Association for Persons with Severe Handicaps has selected an integration theme for its activities which it named the **"Integration Imperative."** It seems to capture the urgency of the matter very aptly and any group who is likeminded is welcome to adopt that theme.

**Community Integration** requires that all services and supports should include, as an essential goal and practice, the enabling of persons with developmental disabilities to participate in and contribute to the life of their communities to the greatest extent possible. They need role models who are not disabled if they are to

learn appropriate personal behaviors and skills. This means that residential assistance should be provided in a person's home which is similar in size and appearance and located in a neighborhood where people without handicaps live. It means that children and adults should go to their local schools with individuals who are not handicapped. They should receive vocational training in secondary and post-secondary schools and/or on-the-job in local businesses or industries where they are employed along side of employees with no handicaps. They should get health care from a variety of health professionals in their offices, community clinics or hospitals. They should receive religious nurture in the church or synagogue they would attend if they were not disabled. And they should participate in social and recreational past-times not only in their own homes but also in public parks, theatres, restaurants, libraries or sport facilities. Engaging with others in smaller groups affords individuals more opportunities to speak and listen, to know and be known by others.

**Quality Services** are those that lead to **Community Integration**. They are designed to help persons who are severely handicapped develop the personal behaviors and skills they need now and in the future to live with and among mostly non-handicapped people. Many programs, organizations and agencies in Minnesota and other states have done this very successfully by using new techniques. They proposed new theories (**state-of-the-art principles**) and used them to design and test new programs. The resulting documentation has shown that persons with the most severe handicaps have made such dramatic gains that expectations for their achievements are higher. These programs and services, developed and tested by respected leaders in the DD field, constitute what is best known as **best professional practice**. They work the most effectively. Use of less effective methods is wasteful.

Not all our readers have the ability or resources to enter into the exciting challenge of developing or testing better methods of providing DD services. But,

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.

no one should ignore the use of the following checklist to test and, if needed, to change services we provide. Community Integration and Quality Services require:

- **personal interaction** - daily living and learning activities that promote interactions mostly with people who aren't handicapped.
- **natural environments and scale** - engaging in daily activities in the places and on the scale that are typical for non-handicapped people.
- **least-restrictive** - services cause little or no disruption to exercise of one's rights or preferences.
- **age appropriate** - use of activities, materials and sites that are consonant with a person's chronological age.
- **functional** - basic behaviors and skills needed to become as self-sufficient as possible.
- **community-referenced** - absolutely needed for life in a typical neighborhood where one must deal with mostly non-disabled people, negative attitudes, physical obstacles, economic constraints, etc.
- **state-of-the-art/best professional practice** - use of advanced (but proven) principles and methods, continuing professional development and creative problem solving.

Future articles will cover topics such as how to effect change, family support and public policy, a supported community living model, professional development/preparation and continuing education and integration for people with challenging behaviors. This new feature is not intended to provide definitive information or specific solutions to problems, but rather to stimulate further reading/study/discussion about new ideas gleaned from a variety of sources.

#### Sources and Recommended Reading:

1. "Developmental Disabilities Regional Policy Plan of the Metropolitan Council", 1985.
2. "The Quality of IEP Objectives Associated with Placement on Integrated Versus Segregated School Sites," by Hunt, Goetz and Anderson. JASH - Summer 1986. Discusses seven indicators of "best practice" that have relevance beyond education programs.
3. Donnellan Criteria for Quality-12 principles listed by Anne Donnellan of the University of Wisconsin-Madison. The list is synthesized from a report to the Court Monitor for Welsh V. Levine by Donnellan and N. Negri-Shoultz. July 1986.

(Available from DD Information Exchange ; 300 Metro

Square Building; St. Paul, MN 55101; or call (612) 291-6427.)

#### ALL-TERRAIN VEHICLES UNSAFE FOR CHILDREN

Children driving all-terrain vehicles risk brain injury according to a report by the Head Injury Service at Gillette Children's Hospital published in Pediatrics, November 1986.

Although popular as recreational vehicles, three-wheelers cause problems for young drivers. Their instability and relatively high center of gravity make handling difficult. Fifteen percent of all the children admitted to Gillette's Pediatric Head Injury Service from 1984 to 1985 were treated for severe brain injuries caused by all-terrain vehicle accidents.

Gillette Children's Hospital recommends that children under the age of 16 should not operate all-terrain vehicles. Before allowing older children to drive all-terrain vehicles, parents should warn them of the hazards, enroll them in safety training programs, and insist that they wear protective helmets.

The manufacturers warn that all-terrain vehicles are not designed for passengers. Passengers aggravate the vehicles' instability.

#### GUARDIANSHIP AND CONSERVATORSHIP

A **guardian** may be an individual, organization, or state agency appointed by a court and given the authority to make decisions on behalf of a person determined by a court to be legally incompetent. A **ward** is a person for whom a guardian has been appointed.

**Conservatorship** in Minnesota is a limited form of guardianship. In other states it may only mean what we call guardian of estate. Conservatorship in Minnesota restricts only those portions of the rights as stated in the court-ordered warrant of conservatorship commitment. It does not take away a person's fundamental civil right to vote and does not deem the person a legally incompetent person. A **conservatee** is a person for whom a conservator has been appointed.

The purpose of a guardianship is to insure that appropriate decisions are made for persons who are unable to make decisions for themselves. This is true for both minors and adult persons who are deemed incompetent. The critical factor is that the person must be unable to make responsible decisions for him or herself.

For more information: Kay C. Hendrikson; Public Guardianship Administrator; Quality Assurance and Protective Services; Fourth Floor, Centennial Office Building; St. Paul, MN 55155.

## RESOURCES/SERVICES

### "Becoming a Surrogate Parent"

A videotape has been produced by PACER which may be used by school districts to provide training for persons who will represent children who are handicapped and have no parents in the special education planning and decision process. For more information: PACER; 4826 Chicago Avenue; Minneapolis, MN 55417; 1-800-53 PACER.

### Writing Class for Adults with Hearing Impairments

The University of Minnesota is offering a writing class during the spring quarter of 1987 for persons who are hearing impaired. For more information: Deb Guthmann; (612) 376-2727 (V/TDD).

### For South Hennepin Area Residents

**"The Learning Exchange"** is a community program that offers a number of recreation and education programs for people with disabilities who live in South Hennepin suburbs. The variety of programs include adapted aquatics, theatre techniques, spring indoor-planting, money management, early childhood family education, relaxation exercises, basic reading and math. These programs are often targeted to people with specific disabilities. For more information: Learning Exchange; Bloomington Education Center; 8900 Portland Avenue; Bloomington, MN 55420; (612) 887-9226 or 887-9144 (TDD).

## REQUEST FOR ASSISTANCE

A parent with a young daughter who has spina-bifida is asking parents of similar children age 10-16 years, to send information they have found useful about medical problems, personal growth, other everyday issues such as expectations, productivity, etc. This communication network will be the start of a nationwide information exchange between parents and among spina-bifida associations. Please send your helpful ideas to: Harold Tillinghost; "Information for Us"; Box 8274; Cranston, RI 02920.

## FOR YOUR INFORMATION

### Parking Still a Problem

Although special parking for persons with handicaps has been mandated by state law there are still problems. Nondisabled persons frequently park in "designated" spaces and enforcement is inconsistent around the state. Public service announcements have been sent to Minnesota newspapers. You are asked to encourage your local paper to use these announcements if they have not done so. You may also encourage your church, fraternal organizations, union and/or employer

newsletter to use the notice. You may request copies of the notice free of charge from the Minnesota State Council for the Handicapped; 208 Metro Square Building; St. Paul, MN 55101; (612) 296-6785 (V/TDD) or toll-free statewide: 1-800-652-974.

### EFA National Toll-Free Service

The Epilepsy Foundation of America announces availability of a nation-wide, toll-free telephone information service. The number is 1-800-EFA-1000. It enables people with epilepsy, their families and the general public to call free of charge to get help and information about epilepsy. The information will cover resources available in the caller's area such as medical services, self-help groups, employment programs and legal assistance.

### Equipment Purchase Funds Available

The Metropolitan Center for Independent Living (MCIL) announces availability of equipment grants for Metro Area persons with disabilities who have no other resources for needed adaptive equipment. To obtain more information: John Walsh, (612) 646-8342.

### Health Education Directory Updated

Community Health Education Network (CHEN) has updated its directory of lending library materials. The November, 1986 directory is now available. CHEN is a program of the Association for Retarded Citizens of Minnesota. For a copy of the directory or more information regarding general health concerns, write or call Sally Swallen; 3225 Lyndale Avenue South; Minneapolis, MN 55408; (612) 827-5641 or toll free in Minnesota 1-800-582-5256. This is a free service of the ARC/MN.

## CONFERENCES

### February 12-13, 1987

#### Child Abuse Prevention: Community Responses

Prevention is the theme of a conference to be held at the Earle Brown Center for Continuing Education on the St. Paul campus of the University of Minnesota. Sponsored by Continuing Education in Social Work, the State of Minnesota Attorney General's Office and Child Abuse and Neglect Association, the conference will identify various community sectors' roles in addressing child abuse prevention -- the medical, religious, school and private sectors.

This conference has been designed for case workers, school social workers, therapists, day care providers, foster parents, residential facility staff, clergy, crisis counselors, pediatric nurses, and child advocates. The registration fee for this two day conference is \$75.

For further information or registration information call Deborah Wolfangerl, Continuing Education in Social Work at (612) 625-3020.

## **FEDERAL HIGHLIGHTS**

### **Reversal of Supreme Court Decision on Air Transportation**

Earlier this year it was reported that the Supreme Court's decision of June, 1986 determined that Section 504 of the Rehabilitation Act of 1973 did not apply to U.S. commercial air carriers except for a few small regional carriers that receive direct federal subsidies.

On October 2, President Reagan signed into law S 2703, the "Air Carriers Access Act of 1986 (PL 99-435). The law reverses the Supreme Court decision by amending the Federal Aviation Act of 1958 (Section 404) that includes language from the Rehabilitation Act which is intended to prevent discrimination against people with handicaps in provision of air transportation.

### **Fair Labor Standards Act Amended**

On Thursday, October 16, President Reagan signed into law P.L. 99-486. This law will simplify Section 14(c) of the Fair Labor Standards Act, eliminating separate certificates for sheltered workshops and creating a new wage system that will more fairly determine the wages of sheltered workshop employees. The major provisions of the bill include the elimination of separate certificates and the requirement that at least 50 percent of the floor space of a workshop be a sheltered workshop; work activity centers no longer have to be separated from regular workshop programs; wage rates and productivity measurements for disabled workers have to be made at least once every six months, while prevailing wages have to be reviewed at least yearly; employers who are currently receiving a paid wage rate that is guaranteed by a certificate from the Department of Labor would receive at least that rate for the next two years; and disabled employees, their parents or guardian may petition the Secretary of Labor for a review of special minimum wage rates by an Administrative Law Judge.

### **New HCFA Guidelines**

The Health Care Financing Administration (HCFA), the agency within HHS that administers the Medicaid program, has issued several new guidelines for state Medicaid agencies. They deal with 1) inappropriate placement of persons with mental retardation and related conditions in nursing homes, and 2) a clarification on "habilitation" services eligible for Medicaid reimbursement. A transmittal, dated August 1986, strengthens the 1982 restrictions under which a state may bill Medicaid for services to a person with mental retardation or related condition in a regular

nursing home. Although the 1982 section required the nursing home to provide necessary developmental services, the new revisions question the placement of persons with mental retardation or related conditions such facilities except for a small percentage who require skilled medical care on an inpatient basis that an ICF/MR cannot provide.

The state Medicaid agency and appropriate county agency should be informed of these requirements. These agencies should monitor compliance to assure that individuals are not placed inappropriately into nursing homes and that individuals who do reside in nursing homes receive active treatment and plan for relocation to an appropriate community living arrangement.

In a September, 1986, mailing to the states, HCFA's transmittal number 21 contains guidelines for federal funding of vocational services: a) no federal financial participation (FFP) is available for services that are required or funded under a state or federal vocational training program, regardless of whether individuals are compensated for their work; and b) if the services are provided by the ICF/MR, FFP is available when the purpose of the activity in which the individual is engaged is to teach him/her the skills necessary to perform tasks in an employment situation.

### **Medicaid Reform**

Friday, September 19, 1986, will be remembered as major day of information and education for members of the Senate Finance Committee's Subcommittee on Health. Under the chairmanship of Senator David Durenberger (MN), the Committee held a hearing to examine Medicaid financing of services for persons with disabilities.

Twenty witnesses, representing the Health Care Financing Administration, leading policy researchers in the field of developmental disabilities, state MR/DD agency directors, providers, advocacy groups, parents, and individuals with disabilities presented testimony. Most of the witnesses, including many from Minnesota, clearly articulated that the current Medicaid long-term-care ICF/MR program and the waiver for home and community based care are "broken and need to be fixed".

In his opening remarks, Senator Durenberger stated that he was not in favor of a dichotomy of institution or community but that we must achieve the highest quality services, maximum freedom, safety, and individual potential to grow. More will follow about Medicaid Reform in subsequent issues.

# INFORMATION EXCHANGE

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## NEW PUBLICATION CALLS FOR A NEW WAY OF THINKING: SUPPORTING A NEW VISION

A new briefing booklet for policy makers in Minnesota will be released in January 1987 entitled *A New Way of Thinking* which is the result of a cooperative effort between the Governor's Planning Council on Developmental Disabilities, State Planning Agency, and the Center for Educational Policy Studies, College of Education, University of Minnesota. This publication provides a summary of what has been learned about people with developmental disabilities over the past few decades, where we are currently with respect to addressing their basic needs, and a framework for future directions--toward a new vision of how all people, regardless of having a disability, can be supported in communities.

This report has basically three messages. First, that there is a new way of thinking about how, where, and with whom people with developmental disabilities can live, learn, and work. Contrasts between the old way and the new are typified in how there has been a shift from a preoccupation with preparation, care, and treatment to a concentration on supporting participation, building on capabilities, adapting environments, and building relationships. Where the old way of thinking offered limited options to persons with developmental disabilities and their families, the new way of thinking means assisting individuals and families in identifying what is important to them, and empowering them with decision making and with spending to act upon those choices.

The second message calls for the exploration of new service strategies and to develop experience with new ways of thinking and acting. Examples are provided in the report of new service models currently being demonstrated in Minnesota, from supported employment and the provision of options in community living to ways in which the quality of programs can be evaluated by those who use the services.

The third message is that the impact of these developments in new policies and services has not yet tipped the balance in the life experiences of people with developmental disabilities and that there is still a long way to go. There are great disparities between what we know and what we actually practice, for example:

- In 1985, approximately 1,500 Minnesota children from birth to age two who would have been eligible for early intervention services were not receiving these services. Yet, it is known that for each dollar invested in preschool education, a savings of \$4.75 is achieved in lower special education costs, reduced welfare payments, and higher worker productivity.

- Emphasis of both policy and legislation is on integration of students with disabilities into regular classroom settings and local schools; yet in 1985, 98 percent of the Minnesota students with moderate and severe mental retardation were attending classes in separate school buildings (35 percent) and in separate classes (63 percent).

- While the benefits of having a real home and the support of meaningful relationships are held in high esteem by advocates, the reality is that less than 1 percent of all residential funds are used to support families--the people most often involved in providing a real home for people with developmental disabilities.

The translation of this new vision into reality will depend upon two changes: (1) major reforms in federal funding to encourage the routine and systematic development of services and supports to individuals as participating and contributing members of their communities; and (2) systematic attention at the state, local, family, and individual levels to ensure that the vision is achieved.

Specific suggestions are provided on what Minnesotans can do to assure a place for persons with developmental disabilities in their communities. It will take a concerted effort by everyone: consumers, parents, policy makers, professionals, board members, friends, neighbors, and citizens in every community. The report ends with suggestions for each of us, for example as a community:

- Think about ways to ensure that people with developmental disabilities have the opportunity to live in homes of their own rather than service settings and to be real neighbors.

- Look around your community and discover who is missing or has had to leave your community because services and supports were not available. Consider what you can do to help them return home.

- Set an agenda for creating a community that

welcomes, includes, and supports people with developmental disabilities.

Copies of **A New Way of Thinking** will automatically be sent to people and agencies on the mailing list of the Governor's Planning Council on Developmental Disabilities after February 1, 1987. Otherwise, copies may be requested from: GPCDD; State Planning Agency, 201 Capitol Square Building; 550 Cedar Street; St. Paul, MN 55101. Tel. (612) 296-4018, or TDD: (612) 296-9962.

### **CANADIANS ENVISION HOW CITIZENS CAN MAKE A DIFFERENCE IN THEIR COMMUNITIES AND PROMOTE LIVES OF QUALITY**

After literally years of talking about how to prevent mental handicaps, the Canadian Association for Community Living (formerly the Canadian Association for the Mentally Retarded), has produced a five-volume series on ***Making a Difference: What Communities Can Do to Prevent Mental Handicap and Promote Lives of Quality***. The series concludes that "We are developing new ways of doing things in communities across the country which demonstrate we cannot only prevent handicapping conditions, but also promote lives of quality." Central to the discussion was the observation that one of the major ways that people with a mental handicap are, in fact, handicapped is the way in which their fundamental rights and freedoms have been denied.

With regard to children, helping them to remain with their families and within their communities is essential in preventing further handicap and promoting lives of quality. The goal of society is to prepare each generation for citizenship, a two-sided coin which not only means having rights that are respected, but the expectation that people will meet their responsibilities as members of a community. Put another way, "Adults are expected to work with their fellow community members to build a strong community, to participate and contribute to the social and economic life of that community.

"We need what John McKnight (professor at Northwestern University) refers to as a 'community vision,' which understands the community as the basic context for enabling people to contribute their gifts", the report emphasizes. McKnight's vision of society is where those who were once labelled, exiled, treated, counseled, advised, and protected are, instead, incorporated into the community where their contributions, capacities, gifts, and fallibilities will allow a network of relationships involving work, recreation, friendship, support, and the political power of being a citizen.

The challenge is not to create better services, though better services are needed. The challenge is to create better communities of support, of self-reliance, and mutual reliance so that our fellow citizens with a mental

handicap can take their rightful place in the community--as respected, participating and contributing citizens, the report concludes.

The complete series of ***Making a Difference*** is available at \$20.00, plus \$2.00 shipping and handling (Canadian dollars), from: G. Allan Roeher Institute Publications; Kinsmen Building, York University Campus; 4700 Keele Street; Downsview, Ontario, CANADA M3J 1P3. Tel. (416) 661-9611.

### **MEDICAID WAIVER PROGRAM UNDER EVALUATION**

An overview of the National Medicaid Home and Community Care Waiver Evaluation Project was recently presented by Robert Clinkscales of LaJolla Management Corporation at a conference entitled, ***Community Service Systems: Accepting the Challenge of Proactive Management*** December 3-5, 1986, held at the Capitol Holiday Inn, Washington, DC. The conference was sponsored by the National Association of State Mental Retardation Program Directors.

The Medicaid Home and Community Care Waiver Program was created with the passage of the Omnibus Budget Reconciliation Act of 1981 (Section 2176) which allowed states to target special home care supportive services to persons who are elderly and disabled, developmentally disabled, and chronically mentally ill in order to provide improved alternatives to often impersonal and more costly institutional care. Following are some of the characteristics about the Waiver Program that resulted from the LaJolla Survey September 1985:

- As of September 30, 1985, there were 75 active waivers in 42 states serving approximately 75,000 persons.
- Persons who were elderly and disabled accounted for two-thirds of the waiver program caseload, or 47,819 persons; the remaining one-third, or 22,218 persons, were served under the waiver program for persons with developmental disabilities or chronic mental illness, of whom most were persons with mental retardation. The average size of an elderly/disabled waiver was 1,195 persons; while developmental disabilities/chronic mental illness waivers were 542 persons.
- Five states (California, Florida, Alabama, Colorado, and New Jersey) accounted for 66 percent of all waiver clients with developmental disabilities/chronic mental illness.
- One-third of the persons with developmental disabilities entered waivers from Intermediate Care Facilities for the Mentally Retarded or institutions; 26 percent were living in their own homes and 28 percent were already living in group residences.
- In terms of expenditures, this is largely a program for persons with developmental disabilities. Although recipients with developmental disabilities accounted for

only one-third of the total waiver caseload, waivers for persons with developmental disabilities accounted for 70 percent of the total expenditures in Fiscal Year 1985 (total reported was \$260 million). This is due to the fact that the annual cost per recipient with a developmental disability was \$6,708, over three times the average annual cost for a recipient who was elderly and disabled at \$2,008.

- About 80 percent of all waivers for recipients with developmental disabilities were for residential and habilitation services.

- Most clients with developmental disabilities were between the ages 22 and 39 and were generally less disabled than the ICF-MR population. Persons with mild or moderate mental retardation comprised only 25 percent of the ICF-MR population but 53 percent of the waiver population. Persons with profound retardation comprised half of the ICF-MR population but only 17 percent of the waiver population.

- Over 52 percent of waived persons with developmental disabilities lived in group homes while another 32 percent lived at home with parents.

- Furthermore, as part of the overall evaluation, case studies have been conducted in California and Georgia; and the findings are still under review by the Health Care Finance Administration.

For more information, contact: Lajolla Management Corporation; 11426 Rockville Pike, Suite 400; Rockville, MD 20852. Tel. (301) 468-0100.

## **PROJECT VOLUNTEERS NEEDED**

Legal Advocacy for Persons with Developmental Disabilities in Minnesota has received a one-year grant from the U.S. Department of Health and Human Services to evaluate whether persons with severe disabilities are receiving quality services designed to meet their individual needs. The first phase of the project will be to design an Individual Habilitation Plan Review Form which will be used to evaluate residential and day programs. The second phase, to begin in early 1987, will use the form to conduct reviews for 30 persons with severe disabilities throughout the state.

If you know of someone or have a family member who has a severe disability who could benefit from an evaluation of a residential and day program, or for more information, contact: Carol Rydell; Legal Advocacy for Persons with Developmental Disabilities in Minnesota; 222 Grain Exchange Building; 323 Fourth Avenue, South; Minneapolis, MN 55415. Tel. (612) 332-1441, or (800) 292-4150, toll free.

## **PUBLICATIONS**

**Parents' Guide to the Development of Preschool Handicapped Children: Resources and Services,**

Library of Congress. This is a new reference guide for parents containing a variety of resources to promote and enhance children's early development. The guide offers sections on children's toys, books, records, magazines, and national organizations of interest to parents. Free copies of the guide may be requested from: National Library Service for the Blind and Physically Handicapped; Library of Congress; Washington, DC 20542. Tel. (202) 287-9275.

**Patterns for Advocacy: How Councils on Developmental Disabilities Achieve Public Policy Goals,** National Association of Developmental Disabilities Councils, 1986. This report describes the activities and accomplishments of Developmental Disabilities Councils in the various states and territories during Fiscal Year 1985. Topics covered include state legislation, interagency cooperation, and the priority areas of the Developmental Disabilities Act--case management, alternative community living arrangements, employment, and child development. Cost is \$7.00 per copy, payable to: NADDC; 1234 Massachusetts Avenue, Northwest, Suite 103; Washington, DC 20005. Tel. (202) 347-1234.

**Frequently Asked Questions about Hiring People Who Have Developmental Disabilities,** National Association of Developmental Disabilities Councils, August 1986. This publication provides answers to questions that employers may have as they consider hiring people with developmental disabilities. The text deals with issues on appropriate placements, training and supervisory programs, subsidy and incentive programs, productivity, wages, accommodations, workers' compensation and other insurance costs, safety, absenteeism, and turnover rates. Specifics on federal programs are also described, such as Targeted Jobs Tax Credit and information systems. Cost is \$6.00 per copy, payable to: NADDC; 1234 Massachusetts Avenue, Northwest, Suite 103; Washington, DC 20005. Tel. (202) 347-1234.

## **CONFERENCES/WORKSHOPS February 1-6, 1987**

**Learning about Normalization through PASS 3** workshop will be held at the Best Western Marshall Inn in Marshall, Minnesota. Program Analysis of Service Systems (PASS) is a tool for assessing the quality of human service programs and serves as an effective means of exploring the principle of normalization and reaching an understanding of the implications of this principle on the planning and delivery of services to people with disabilities. Co-sponsors include: Minnesota Supported Employment Project, Governor's Planning Council on Developmental Disabilities, Minnesota Association for Persons with Severe Handicaps, Association for Retarded Citizens, and Creative Community Options. Cost: \$195.00. For more information and for registration, contact: Creative Community Options; 4209 Oakmede Lane; White Bear Lake, MN 55110. Tel. (612) 426-9263.

## 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.**

**Coordinating Services to Handicapped Children: A Handbook for Interagency Collaboration**, P. Magrab, and J. Elder (Eds.), Brookes Publishers, 1980. This book is designed for educators, professionals, paraprofessionals, and administrators in all of the human service delivery systems for use as a handbook to promote and initiate workable solutions to the problems and issues of delivering services to children with handicaps across the various delivery systems. The subject of interagency collaboration is examined both as a process and as an attitude when working cooperatively together toward the benefit of the individual client, not the agencies providing the service. A suggested format for developing and writing interagency agreements are of particular value.

**Teacher Supervision through Behavioral Objectives: An Operationally Described System**, T. J. Piper, and D. B. Elgart, Brookes Publishers, 1979. The authors of this book believe that the process of teacher supervision can be the greatest contributing factor in improving the quality of education. This text defines the qualities that good teachers display and then provides the forms and means for measuring those qualities. Accurate, meaningful supervision, when conducted in a systematic, quantifiable manner, offers the best indicator of whether skills being used are successful and appropriate. This document serves as a guide to teachers on how to do their own classroom research. It also shows teachers how to develop new ideas about educational programming, curriculum, and successful arrangement of the learning environment.

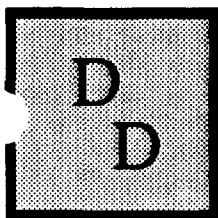
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Recently I read a list of suggestions about the quality theme advanced by Colleen Wieck, Executive Director of the Minnesota Governor's Planning Council on Developmental Disabilities. One suggestion was to shift our focus from "quality care" to "quality of life of the individual" (receiving services). This means moving from the narrower view of services provided (input) to evaluation of what effects services have on the individual (outcome). That type of evaluation requires us to **observe the person** receiving the services in order to **measure changes** (in skills, behaviors, satisfaction, status, etc.) and **record findings** to document the effects. This shift to a "quality of life" focus will be reflected henceforth in this series.

**FAMILY SUPPORT SERVICES.** One of the most important strategies to achieve genuine community integration and a quality of life that every Minnesotan seeks is to assist families who have children with developmental disabilities maintain their children in their own homes. Yet a recent study ("A New Way of Thinking", Governor's Planning Council on Developmental Disabilities, Minnesota State Planning Agency, January 1987) indicates that only one percent of public funds in Minnesota are spent on direct family support services. The remainder is spent for individuals who are receiving out-of-home services even though these figures do not reflect the actual proportion in either group.

A restatement of public policy is needed in Minnesota that recognizes the value of family support and provides adequate funding for its provision. The following principles on family support should shape this new Minnesota policy. The principles are reprinted from a

statement developed at a Policy Institute in June 1986, sponsored by the Center on Human Policy's Research and Training Center on Community Integration located at Syracuse University in New York. The Policy Institute included parents, people with disabilities, professionals and state and national leaders committed to community integration.

"Whereas: All children, regardless of disability, belong with families and need enduring relationships with adults, States and agencies have traditionally not supported the role of families in caring for disabled children.

Therefore: These principles should guide public policy toward families of children with developmental disabilities ... and the actions of states and agencies when they become involved with families:

- \* **Every child should have the right to a permanent home and a stable relationship with one or more adults.** When states or agencies become involved with families, permanent planning should be a guiding philosophy. As a philosophy, permanency planning endorses children's rights to a nurturing home and consistent relationships with adults. As a guide to state and agency practice, permanency planning requires encouragement of family's relationship with the child, family reunification for children placed out of home, and the pursuit of adoption for children when family reunification is not possible.
- \* **Families should receive the supports necessary to maintain their children at home.** Family support services must be based on the principle "whatever it takes," within the limitations of what states and agencies can accomplish. In short, family support services should be flexible, individualized, and designed to meet the diverse needs of families.
- \* **Family supports should build on existing social networks and natural sources of support.** As a guiding principle, natural sources of support,

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.

including neighbors, extended families, friends, and community associations, should be preferred over agency programs and professional services. When states or agencies become involved with families, they should support existing social networks, strengthen natural sources of support, and help build connections to existing community resources. When natural sources of support cannot meet the needs of families, professional or agency-operated support services should be available.

- \* **Family supports should maximize the family's control over the services and supports they receive.** Family support services must be based on the assumption that families, rather than states and agencies, are in the best position to determine their needs.
- \* **Family supports should support the entire family.** Family support services should be defined broadly in terms of the needs of the entire family, including children with disabilities, parents, and siblings.
- \* **Family support services should encourage the integration of children with disabilities into the community.** Family support services should be designed to maximize community integration and participation in community life for children with disabilities.

When children cannot remain with their families for whatever reason, out-of-home placement should be viewed initially as a temporary arrangement and efforts should be directed toward reuniting the family.

Consistent with the philosophy of permanency planning, children should live with their families whenever possible. When, due to family crisis or other circumstances, children must leave their families, efforts should be directed at encouraging and enabling families to be reunited.

- \* **When families cannot be reunited and when active parental involvement is absent, adoption should be aggressively pursued.** In fulfillment of each child's right to a stable family and an enduring relationship with one or more adults, adoption should be pursued for children whose ties with their families have been broken. Whenever possible, families should be involved in adoption planning and, in all cases, should be treated with sensitivity and respect. When adoption is pursued, the possibility of open adoption, whereby families maintain involvement with a child, should be seriously considered.

While a preferred alternative to any group setting or out-of-home placement, foster care should only be pursued when children cannot live with their families or with adoptive families.

- \* **After families and adoptive families, children should have the opportunity to live with foster**

**families.** Foster family care can provide children with a home atmosphere and warm relationships and is preferable to group settings and other placements. Foster care should not be viewed as an acceptable alternative to fulfilling each child's right to a stable home and enduring relationships."

For more information, write: The Center of Human Policy; 724 Comstock Avenue; Syracuse, New York, 13244-4230.

## ANOTHER DIMENSION OF EDUCATION INTEGRATION

Publication of a reprint from "OSERS News in Print", U.S. Department of Education, in our December 1986 issue, prompted a request by a reader to consider inclusion of another perspective from the same OSERS newsletter. The first article presented examples of what Integration DOES mean and what it DOES NOT mean. The following is a reprint of Madeline Will's comments in the same issue of the newsletter. Ms. Will is Assistant Secretary of OSERS.

### "Clarifying the Standards: Placement in a Least Restrictive Environment

Some people have interpreted the Least Restrictive Environment (LRE) to mean that all handicapped students would be placed in a regular classroom regardless of their educational needs, and that a child would have to fail in a regular classroom before special services would be provided. Such is not OSERS' intent.

OSERS' goal is to ensure that:

- Each handicapped child's education placement is determined annually.
- The placement is based on his or her individual education program (IEP).
- A continuum of alternative placement is available to meet the needs of handicapped children for special education and related services. The continuum includes regular classes, special classes, special schools, home instruction in hospitals and institutions.
- Each child is educated in the LRE appropriate to that child.

The overriding principle is that placement decisions must be made on an individual basis and that various alternative placements must be available in order to ensure that each handicapped child receives an education which is appropriate to his or her individual needs.

Findings in the past indicate that placements sometimes are not based on the unique educational needs of the individual child. Placement decisions may have been determined by the availability of space, transportation, or required related services or by the category of handicapped condition.

Therefore, we are reviewing the process by which placement decisions are being made. In order for the LRE requirements to be met, written procedures for placement decisions must be in place. The standards OSERS developed can be used as guidelines to assist states in the development of their own guidelines.

OSERS has received numerous comments and suggestions on the implementation of LRE. We are reviewing these comments carefully and intend to revise our standards to more clearly reflect the intent expressed in this statement."

Space does not permit an analysis of apparently conflicting statements in these two articles both of which appear in the OSERS' publication. Nevertheless, the overriding principle must be that program decisions (whether in the context of education, living arrangements or employment) should be based on the individual's need to function now and in the future in a society where most people do not have handicaps. Today's students who are not disabled are tomorrow's neighbors, law-makers, funders, employers, service providers, religious and community leaders. Without daily and long term personal contact in all types of activities, the non-handicapped members of the community will never be accurately informed about nor adequately responsive to the rights and needs of people who are handicapped.

#### **MINNESOTA SUPPORTED EMPLOYMENT PROJECT**

The Supported Employment Project is committed to providing maximum opportunity for all interested parties to communicate as directly as possible with Project principals over the next four years. The project also is committed to creating a consumer/provider/employer partnership as supported employment is promoted in Minnesota. There are several options available for persons to communicate directly with the Project:

- \* Phone calls to staff: (612) 296-5629 or toll free: 1-800-328-9095, V/TDD;
- \* Participation in or attendance at work group meetings dealing with specific aspects of the supported employment transition;
- \* Presentations/meetings with project staff;
- \* Periodic conferences, hearings, symposiums (e.g. "Values Clarification Training" scheduled for February 23-24; "Supported Employment Strategies" in April in the Twin Cities). For other training activities in greater Minnesota, write or call the Project.

The Supported Employment Project has announced a Request for Proposals (RFP) for assistance in converting from traditional, segregated vocational services to those which result in supported employment outcomes. For further information on any of these activities, write or call: Supported Employment Project; Division of Rehabilitation Services - 5th Floor; 390 N. Robert Street;

St. Paul, MN 55101; (612) 296-5629 or 1-800-328-9095, V/TDD.

#### **PACER SPRING WORKSHOPS FOR METRO AREA**

PACER (Parent Advocacy Coalition for Educational Rights) will sponsor several workshops in the Metro Area:

- \* **February 7, 1987:** "The Least Restrictive Environment"
- \* **February 26, 1987:** "Parents of Preschoolers with Handicaps".
- \* **March 2, 1987 and again on March 9, 1987:** "Special Education Laws and Procedures".
- \* **March 16, 1987:** "Communication Skills".

For a brochure with further information on presenters, time, location and registration details, write or call PACER Center; 4826 Chicago Avenue; Minneapolis, MN 55417; (612) 827-2966, V/TDD.

#### **THE DIFFERENT TYPES OF GUARDIANSHIP IN MINNESOTA**

In Minnesota, there are three types of guardianship:

1. Commissioner's (state) guardianship for dependent and neglected children. This involves a state agency acting as guardian for children whose parental rights have been terminated. The Commissioner delegates supervision and the majority of consents to local social service agencies. This guardianship ends at age 18. Commissioner's guardianship for dependent and neglected children is governed by Minnesota Statutes, section 260.242 as an effect of Minnesota Statutes, section 260.241.
2. Commissioner's (state) guardianship/conservatorship for mentally retarded adults. This involves a state agency acting as guardian for mentally retarded adults who typically do not have family or friends to act on their behalf. The majority of powers of the guardian have been delegated to the local county social worker. Commissioner's guardianship for mentally retarded adults is governed by Minnesota Statutes, section 252A, the Mental Retardation Protection Act.
3. Private guardianship/conservatorship. This involves a private party, such as a relative or close friend, assuming the role of guardian. Private guardianship is generally considered less restrictive than public guardianship. This type of guardianship is governed by Minnesota Statutes, sections 525.539 to 525.61.

Miscellaneous types: The private guardianship law allows the county to act as guardian for those vulnerable adults in danger of serious abuse or neglect. This has been typically used for elder persons. There are also a few small corporations in Minnesota which provide guardianship services for various populations.

For more information contact: Kay C. Hendrikson; Public Guardianship Administrator; Quality Assurance and

Protective Services; Fourth Floor, Centennial Office Building; St. Paul, MN 55155.

## RESOURCES

### Audio Cassettes on Alternatives to Punishment

High quality audio cassettes recorded at a recent symposium sponsored by Community Services for Autistic Adults and Children are now available. The proceedings are entitled, "Alternatives to Punishment in the Management of Severe Behavior Disorders". Speakers include Anne Donnellan, Ph.D.; Gary LaVigna, Ph.D.; Tom Nerney and others. Cassettes are \$8.00 each with reductions when six or more are ordered. To request a brochure with a complete listing, prices and mail order form, write to Recorded Resources Corporation; 1468 Crofton Parkway; Crofton, MD 21114; (301) 858-0026.

### Public Awareness

"Guidelines for Reporting and Writing about People with Disabilities" is a package of colored brochures to use or to disseminate to your local media. Produced by the Research and Training Center on Independent Living at the University of Kansas in Lawrence, this brochure package contains the "Dos" and "Don'ts" of proper terminology. The guidelines reflect input from over 50 national disability organizations and have been reviewed and endorsed by media and disability experts. When ordering, the first copy of this package is free; up to 200 are \$.15/copy, over 200 are \$.10/copy. Contact: Susan Elkins; RTC/IL Training Department; University of Kansas; BCR/348 Hayworth; Lawrence, KS 66045-2930; (913) 842-7694.

### Planning Workbook for Nonprofit Organizations

"Strategic Planning Workbook for Nonprofit Organizations," a free resource produced by the Amherst H. Wilder Foundation and underwritten by the First Banks, Minneapolis and St. Paul, is available. The 88-paged workbook is based on experiences of the Management Support Services division of the foundation, which developed a format to help nonprofits do strategic planning in 1982. The format can reduce planning time by approximately 80 percent in most cases. Follow-up on organizations using the method showed 100 percent of the nonprofits continuing to use the plan and 88 percent of the nonprofits meeting or exceeding the set objectives.

The workbook has three parts: 1) an introduction to strategic planning; 2) a step-by-step guide to develop the plan; and 3) examples of organization strategic plans with removable work sheets. One free copy of the workbook will be sent if you write on your organization stationery to Management Support Services; Amherst H. Wilder Foundation; 919 LaFond; St. Paul, MN 55104.

## 1986 Edition of Guide to Giving

A thoroughly researched and updated edition of *GUIDE TO MINNESOTA FOUNDATIONS AND CORPORATE GIVING PROGRAMS* lists more than 400 Minnesota funders.

Each entry contains data to help nonprofit organizations match their funding needs to the interests of grantmakers. Included among the foundation and corporate listings is vital information such as the grantmaker's purpose, its areas of interest; its geographic requirements; whom to contact for information; when and how to contact; information on assets; the size and number of grants given; a listing of some of the organizations receiving recent grants and the amount of the grants; directors, and more.

In addition, the *GUIDE* contains information on other resources to use in a funding search. It has current information on philanthropy in Minnesota and describes the types of grantmakers working in the state. Indexes simplify the search for funding by offering topical information. The *GUIDE* is published and made available by the Minnesota Council on Foundations. Cost of the guide is \$25.00 plus \$1.50 tax or tax exempt number. Send order and check to the Minnesota Council on Foundations; 425 Peavey Building; 730 Second Avenue S.; Minneapolis, MN 55402.

## FOR YOUR INFORMATION

### Training Opportunity

The spring quarter of *Work Site Training for Persons with Mild, Moderate and Severe Handicaps* will begin March 30, 1987 at St. Paul TVI. The course is offered through the U of M's Vocational Education Department's Special Service Division (624-1700 for more information). It will run for 10 weeks, 3 hours every Monday evening and be taught by Terry Kayser from Metropolitan Council and Marnie Mellberg from Minnesota Diversified Industries. A new focus on *liability issues* will be included this quarter, and will be applied to all phases and aspects of placement and training in community based programs. Pre-registration is required two weeks before classes start.

### Graduate Fellowships Available

The University of Vermont offers one year (including two summers) M.Ed. and Certificate of Advanced Study programs to prepare employment and training transition specialists. Programs include coursework, intensive internships, and opportunities to participate in related research and model demonstration efforts. Employment and training transition specialists are employed in school districts and non-profit agencies to provide community-based vocational training, employment placement, and follow-up services to youth with

moderate and severe handicapping conditions. Graduate assistantships are available for a limited number of qualified individuals. For more information, write to Susan Brody Hasazi, Ed.D., Program Director; 405 Waterman Building; University of Vermont; Burlington, Vermont 05405; (802) 656-2936.

### **National Report on Independent Living Centers**

A recently completed report by Berkeley Planning Associates (BPA), evaluated Title VII, Part B, Centers for Independent Living Programs for 1984-85. The study found that this program overall is helping many disabled citizens live independently in their communities through individual and direct services, referrals, and activities for community change.

There is a great diversity across the country in client population, services offered, management practices and systems, and the involvement of persons with disabilities in center planning and management. Some diversity is appropriate for local needs, but BPA found that many centers would benefit from more guidance and technical assistance, greater information exchange with other centers, and increased levels of stable funding. In addition, the centers collect a wealth of information that could be more valuable to program and policy planners if definitions and measures were uniform across the centers. Contact Linda Toms Baker, Project Director at BPA at (415) 652-0999, if you want a copy of the full report or executive summary of the study. (Ed. Note: No address available.)

### **A NEW CASEMANAGEMENT APPROACH**

A new program called **Parent Case Management** has begun at the Association for Retarded Citizens Suburban. A grant was received from the Governor's Planning Council on Developmental Disabilities to fund the program. The intent of the program is to empower parents and/or guardians in Dakota, Scott and South Washington counties to act as case managers for their children with developmental disabilities. The social worker would maintain the supporting role that is so necessary to sustain a capacity to function well as an individual or family.

For being part of this exciting program parent case managers will receive training, support and monetary compensation. Two initial workshops are being scheduled and open to the public on Saturday, March 14 and Saturday, March 21, 8:30 a.m. to 3:00 p.m. in the Community Action Council Building, 14451 County Road 11, Burnsville.

Topics and speakers are:

**Case Management and Rule 185** - Shirley Shue

**Identifying needs and services** - Jennifer Otto

**Roles of persons in the project** - Cathy Ellis

**Writing quality goals and objectives** - Robert Prouty

**State of the Art service delivery** - Edward Skanulis

### **Networking - Georgi Larson**

Please call 431-3700 to pre-register. If you would like to become a parent case manager or receive mailings about training, call Marijo McBride - ARC Suburban - 431-3700.

## **CONFERENCES/WORKSHOPS**

**February 27, 1987**

### **Cooperation Strategies: Resolving Conflict and Dealing with Anger**

Minnesota Educators of the Emotionally Disturbed (MEED) and Staples Vocational Technical Institute Extension Services will co-sponsor this workshop at the St. Louis Park Holiday Inn, Highways 12 and 18, from 9:00 a.m. to 4:00 p.m. Dr. Mary Tjosvold, educator and author, will present this workshop which is designed for educators, human service personnel, administrators, psychologists, social workers and nurses. The strategies presented will have practical application to the work of these professional groups. For registration form or more information: Gordon Wrobel; MEED; 1500 Glenwood Avenue N.; Minneapolis, MN 55405; (612) 627-3175.

**February 28, 1987**

### **"Mainstream Education for Hearing Impaired Students: Language and Amplification Implications"**

This workshop will be presented at the St. Paul Radisson Hotel, from 8:15 a.m. to 3:15 p.m. Presenters will be Richard R. Kretschmer, Ed.D., Laura W. Kretschmer, Ed.D. Cosponsored by the Minnesota Foundation for Better Hearing and Speech and the Minnesota State Department of Education. For more information call Linda Oberg at 223-5140 V/TDD or Christina Clarke at 296-5605.

## **RECREATION/LEISURE ACTIVITIES**

### **Junior Bowling League**

A program designed for hearing impaired children ages 7-17 will be held at Midway Pro Bowl every Friday from 4 to 6 p.m., February 20, 27, and March 6, 13, 20, and 27. The enrollment is limited to 16 participants. Cost is \$4/session. Register through the Minneapolis Park and Recreation Board; Fuller Park; 4800 Grand Ave. S.; Minneapolis, MN, (612) 348-4970.

## **REQUEST FOR ASSISTANCE**

### **Information Network**

Seeking providers, professionals interested in shared training, idea exchange, networking with others who are providing residential and work programs for clients who are both hearing and vision impaired, as well as developmentally disabled. Contact Carol Lee; Harry Meyering Center; P.O. Box 302; 109 Homestead Drive;

## Volunteer Opportunities

Would you be interested in having some fun enjoying your favorite activities while sharing some time with someone who has the same interests? ARC Suburban is looking for singles or couples to accompany persons with mental retardation one or two times a month to community activities such as movies, restaurants, winter sports, dances, classes, etc. ARC Suburban will reimburse admission, cost of classes, meals, and mileage. We will match you with one or two individuals who share your interests. No experience necessary. Training will be provided. Call Mary Ellen at 431-3700 for more information. The Association for Retarded Citizens Suburban is a private non-profit organization serving Dakota, Scott and south Washington counties.

## PUBLICATIONS

*"Public Expenditures for Mental Retardation and Developmental Disabilities in the United States: State Profiles (Second Edition),"* by David Braddock, Ph.D., Richard Hemp, M.A. and Glenn Fujiura, Ph.D., University of Illinois at Chicago. This report summarizes FY 77-86 spending in the states for services to individuals with mental retardation and related developmental disabilities. This document presents for each state a graphic fiscal profile, detailed technical notes documenting sources of data and the basic organization of services within a given state. The monograph covers four basic areas:

- 1) budgeting characteristics in MR/DD agencies and spending trends in the states;
- 2) national charts of all states in terms of revenue sources, institutional services data, and state rankings of fiscal efforts;
- 3) individual state profiles; and
- 4) Federal Income Maintenance data.

This Public Policy Monograph (29) is available from the Evaluation Public Policy Program; 1640 West Roosevelt Road; Chicago, IL 60608, at a cost of \$30.00. Make your check or money order payable to the Evaluation Public Policy Program.

## FEDERAL HIGHLIGHTS

### NIHR Grant on Family Support Policy

The National Institute of Handicapped Research of the Department of Education has awarded a three-year grant to the Human Services Research Institute in Cambridge, Mass., to identify exemplary models for designing and financing home care for children with severe disabilities and chronic illnesses. The goal of this project is to define flexible, yet effective mechanisms, to support and sustain family care for these children. In identifying state-of-the-art practices and financing options, the

Institute will address several major objectives:

- \* To identify the costs of providing home care and the factors which contribute to these costs;
- \* To develop alternative models for financing home care using a variety of public and private sources; and
- \* To evaluate the effectiveness and feasibility of alternative financing models following implementation at demonstration sites.

The project will first identify those variables that are critical in assessing the financial burden of providing home care. During the second phase of the project, states will be asked to submit proposals for the development of demonstration projects using new models for financing and supporting home care. The selection of demonstration sites will be based upon the following criteria: the involvement of key public and private sector agencies, the overall impact of the project on the well-being of families, the probability of success and subsequent acceptance of the model, and the level of commitment of the sponsoring agency.

The project will also include several national symposia which will introduce participants to alternative financing models and provide an opportunity for the liaison network and other public and private agency representatives to participate in a critical review of issues and policies affecting the capacities of families to provide care and support in their own homes. For additional information about this project contact: Allan I. Bergman; Governmental Activities; United Cerebral Palsy Associations; (202) 842-1266 or Valerie Bradley, Deputy Director; Human Services Research Institute; 336 Massachusetts Avenue; Cambridge, Massachusetts 02140; (617) 876-0426.

### GAO Report on Special Education Financing

*"Special Education: Financing Health and Educational Services for Handicapped Children"* (GAO-HRD-86-62, July 31). Because of concerns that the Education for all Handicapped Children's Act caused state and local education agencies to assume increased responsibilities for services to handicapped children, GAO (Government Accounting Office) has obtained information on the use of interagency agreements in Connecticut and Maryland as a method of using state agency resources to help finance these costs.

In Connecticut, about \$5 million per year in Medicaid reimbursements will be made to school districts for school-based health services to handicapped children. In Maryland, the interagency agreement resulted in education, health and social service agencies contributing \$11 million to a FY 86 state funding pool to cover costs of placing children with handicaps. To obtain a copy of the report, contact the U.S. General Accounting Office; P.O. Box 6015; Gaithersburg, MD 20877 (order by number).

# INFORMATION EXCHANGE

STATE  
SUPPLEMENT

Developmental Disabilities Program

201 Capitol Square Building

550 Cedar St.

St. Paul, Minnesota 55101

Minnesota State Planning Agency

Roger Strand, Editor

612/296-4018

Member of

National Association of

Developmental Disabilities

Councils

February 1987



## COURT MONITOR NOTES IMPROVEMENTS, BUT SERIOUS PROBLEMS PERSIST

In a sixth report to the Federal District Court of Minnesota (December 1986), Richard Cohen, Court Monitor for the *Welsch* Consent Decree, concluded that although improvements have been made by Minnesota's seven regional treatment centers (formerly called state hospitals) for persons with mental retardation, there are still serious and generally pervasive problems at each regional center. During the past several months, each center has been reviewed and evaluated by outside consultants who were retained from Minnesota and other parts of the country. Their findings were combined with data kept by the Court Monitor in the production of this report.

Noteworthy progress has been made with respect to population reduction. The Decree had set an overall institutional reduction of not more than 1,850 by July 1, 1987. This deadline has already been reached, one year ahead of schedule. As of July 1, 1986, the overall census at the seven regional centers dropped to 1,845. The Department of Human Services is projecting further reduction by June 1987 to 1,522. Cohen concluded that the moratorium (which was placed by the Legislature on further development of ICF/MR facilities) has obviously not prevented the required population reduction. In addition, because of reduced census, the staffing ratios have maintained general compliance with the Decree.

Although target reductions in populations have been exceeded, notes the Monitor, the population reduction data together with other information indicate that identifiable groups, such as residents who are behaviorally involved or who have certain physical handicaps, may have been excluded from the community placement process. "There appear to be official and unofficial practices and policies which tend to support discriminatory behavior, or at the very least, do not adequately address or prevent discriminatory practices," Cohen stated in the report. He further stated that, Since the beginning of the Decree, persons with severe physical handicaps or behavior problems have been excluded from community placement efforts, based solely or in part on their handicap.

Admissions have decreased, both for respite care and non-respite, but according to the Court Monitor, many admissions remain preventable. Initiatives by the

Department of Human Services to promote family respite care is one of the primary reasons for the reduction, and in all probability will result in further reductions in the future, the Monitor indicated.

The Decree had placed a one-year limitation on the stay of children in state facilities. Previously, several children were residing longer than a year. None are today. Once recommendations are made (regarding community placements for children), stated Cohen, the Department of Human Services and the counties have been generally cooperative in arranging or developing services to facilitate placement within the newly established discharge date. Cohen concluded, It has become clear that not unlike their adult counterparts, most, if not all, of the children could have remained in the community had the services been planned for and arranged to begin with.

Regarding discharges and placements, progress has been made with respect to the avoidance of inappropriate placements in nursing homes, the use and monitoring of psychotropic and anticonvulsant medications, and availability of staff trained in cardiopulmonary resuscitation (CPR). On the other hand, considerable outstanding issues remain in the assessment of individual needs for community placement, the adequacy of discharge plans, the appropriateness of residential placements, individual habilitation plans, and the appropriateness of educational, developmental, or work programs. Cohen noted the lack of enforcement of standards to guide or direct personnel in the entire placement process, which results in considerable variability in performance and quality of the process, as well as the actual placement.

The adequacy, both in quantity and quality, of county case management services throughout the state continues to be a primary concern. Cohen noted that it is unfortunate that the Minnesota rules governing case management do not appear to be uniformly applied or enforced.

Although all or nearly all residents in regional treatment centers now have individual habilitation plans, Cohen noted, numerous deficiencies continue to be reported by consultants. Despite some excellent examples of integrated and functional approaches, there continues to be an overall major failing at all facilities in this area, particularly for persons with physical handicaps. Functional skills are frequently taught in non-functional situations or contexts and therefore do not promote true skill acquisition or generalization. Programs for



persons with behavior problems are frequently inadequate and overly reliant on mechanical restraint, seclusion, or other aversive and deprivation procedures.

Physical environments at the seven facilities have been improved, but the environments remain deficient in the level of activity, staff-resident and resident-resident interaction, homogeneous grouping of class members, and mealtime atmosphere. Serious problems remain in staff training and supervision, expectations, and in some cases, deployment. These environmental influences can hinder proper implementation of teaching programs and, in fact, may contribute to problem behaviors of class members, Cohen suggested.

Cohen concluded in the report, "The deep rooted and pervasive nature of these problems and the failure to sustain a true and aggressive quality assurance effort provides further evidence for the need of a strong and independent quality assurance mechanism."

A copy of the summary introduction to the report is available upon request from: Governor's Planning Council on Developmental Disabilities; 201 Capitol Square Building; 550 Cedar Avenue; St. Paul, MN 55101. Tel. (612) 296-4018.

#### **CASE MANAGEMENT REQUEST FOR PROPOSALS TO BE ISSUED**

On February 4, 1987, the Governor's Planning Council on Developmental Disabilities reviewed the Request for Proposals (RFP) for the second year of funding for projects relating to case management. The improvement of Minnesota's case management system is the Council's first priority, as stated in the Council's Three-Year State Plan. Last January 1986, a Request for Proposal was distributed which resulted in the funding of six projects for the year, October 1986 to September 1987. Based on work already completed by the first-year projects and developments that have taken place in Minnesota, changes were made in the Request for Proposal. The Request for Proposal will be mailed to potential applicants about February 10, 1987. If a copy of the RFP is not received by the end of February 1987, please call Ron Kaliszewski, Grant Administrator, at (612) 297-3207.

#### **AWARENESS MONTH POSTERS AVAILABLE**

A limited supply of posters are available that can be used to celebrate Developmental Disabilities Awareness Month, which occurs during the month of March 1987. The posters can be picked up at the Governor's Planning Council on Developmental Disabilities, 201 Capitol Square Building, 550 Cedar Street, St. Paul, MN 55101. Tel. (612) 296-4018.

#### **APARTMENT LIVING PLANNED IN HIBBING**

Accessible Space, Inc, based in St. Paul, has received approval from the Housing and Urban Development

Department (HUD) to develop an eighteen unit accessible, subsidized apartment building in Hibbing, Minnesota. A \$660,900 low-interest loan from HUD will provide the needed construction money for the project and rental subsidies through the Section 8 Program will provide assistance to low-income residents with disabilities.

Accessible Space, Inc. has as its mission to provide affordable, community-based, independent and semi-independent living opportunities for persons with mobility impairments and brain injuries. It is anticipated that the Hibbing apartment complex will be ready for occupancy in approximately two years. Services provided to residents will include personal attendant care, cooking, cleaning, and additional support services. For more information, contact: Stephen Vander Schaaf, Executive Director; Accessible Space, Inc.; 2550 University Avenue, West (Suite 301 N); St. Paul, MN 55114. Tel. (612) 645-7271.

#### **PROJECT CHALLENGE IN ST. CLOUD PROMOTES COMMUNITY INTEGRATION OF PERSONS WITH DISABILITIES**

Life-long learning opportunities are available to adults with disabilities through Project Challenge in St. Cloud, Minnesota, which is part of District 742 Community Education Program. The project provides inservice training to area human service professionals, as well as coordination of special events which foster opportunities for persons with disabilities to interact with non-disabled persons, such as recreation. In addition, individualized functional skill training is available to adults with special needs. For further information, contact: Mary Bauer; Community Education, District 742 Community Schools; North Community School; 1212 North 29 Avenue; St. Cloud, MN 56301. Tel. (612) 251-1733.

#### **PUBLICATIONS**

**Breaking Barriers: How Children and Adults with Severe Handicaps Can Access the World through Simple Technology**, J. Levin, & L. Scherfenberg, ABLENET, Minneapolis, 1987. This is a resource guide for parents, teachers, and therapists who want to learn more about the functional applications of simple technology in home, school, and work settings. The guide illustrates how the use of automated learning devices (ALDs), one form of simple technology, can help persons with handicaps to access new experiences, new activities, and new environments. ALDs can allow the user to independently control electrical appliances or battery-operated toys. A variety of activities and resources are provided, all of which are geared to encourage active participation, success, and independence by children and adults with disabilities. Cost: \$14.80, including sales tax, shipping and handling. Contact: ABLENET; 360 Hoover Street, N.E.; Minneapolis, MN 55413. Tel. (612) 331-5958.



**Alternatives Today** is a bi-monthly newsletter for business-minded, not-for-profit managers, board members and government agency heads. Its purpose is to explore income diversification and to promote solid management. Annual subscription is \$12.00, made payable to: Corporate Alternatives, Inc.; P.O. Box 1613; Springfield, IL 62705. Tel. (217) 544-5687.

**Standards Manual for Organizations Serving People with Disabilities, 1987 Edition**, Commission on Accreditation of Rehabilitation Facilities (CARF). This new edition replaces the existing CARF Manual. The manual is recognized as a key management tool and blueprint for organization and program planning. For the first time, standards regarding supported employment have been included. Other standards have been revised in the areas of vocational evaluation, work adjustment, occupational skill training, job placement, and work services. Cost: \$25.00. A revised *Self-Study Questionnaire* is also available at \$15.00. Contact: CARF; 2500 North Pantano Road; Tucson, Arizona 85715. Tel. (602) 886-8575.

## CONFERENCES/WORKSHOPS

### February 6, 1987, (4:00-6:00 p.m.)

Gillette Children's Hospital invites the public to the opening of its new Motion Laboratory on the first floor of the Ramsey medical campus in St. Paul. Motion analysis (using electronic-image processing to analyze muscle, joint and nerve problems) will be demonstrated. For further information, call: (612) 291-2848, extension 256.

**"Understanding the Multi-Disciplinary Approach to Child Sexual Abuse"** is a one-day workshop scheduled in three different areas of the state. The workshop is sponsored by Project Impact of the Minnesota Interagency Team on Child Abuse, and is designed for professionals. Dates and places are as follows:

**February 10**--Spring Hill Conference Center, Wayzata

**February 26**--Quadna Mountain Resort Hill City

**March 5**--New Ulm Holiday Inn

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

### February 23 and 24, 1987

**"Values Clarification Training"** is a workshop funded and sponsored by the Minnesota Supported Employment Project and the Government Training Service. This is the second of three workshops planned in Minnesota, and will be held at the Ramada Hotel in St. Paul. The overall purpose will be to explore some of the critical issues involved in providing integrated community services to people with severe disabilities. Presentations will be given by Jane Wells, Creative Community Options, White Bear Lake, and Charles Hopkins, Community Developments Services, Dalton, Georgia. Cost: \$35.00. For more information contact: Government Training Service; Minnesota Building, Suite

202; 46 East Fourth Street; St. Paul, Minnesota 55101. (Note: The third regional workshop is scheduled for April 23-24, 1987, at the Holiday Inn in Bemidji.)

### March 5, 1987

The 1987 Day at the Capitol theme will be **"Community Services--Community Supports,"** sponsored by the Association for Retarded Citizens (ARC) Minnesota. The workshop will begin at the Holiday Inn-State Capitol in St. Paul. Cost: \$12.00, which includes lunch. Contact: ARC Minnesota; 3225 Lyndale Avenue South; Minneapolis, MN 55408. Tel. (612) 827-5641, or (800) 582-5256, toll free.

### April 9-11, 1987

The Minnesota Speech-Language-Hearing Association annual Spring Convention is scheduled for April 9-11 at the Sheraton Park Place Hotel, Minneapolis, Minnesota. Keynote speaker will be the immediate past president of the American Speech-Language-Hearing Association (ASHA), Betty Jane Phillips. A variety of issues in audiology, speech and language pathology will be discussed by nationally recognized speakers. A number of local speech-language pathologists and audiologists will also present current information pertinent to communication disorders. Some of the presentations include: **Issues in Language Disorders** - Dr. Richard Schwartz, Purdue University; **Augmentative Communication** - Dr. Joe Reichle, University of Minnesota; **Neurogenic Communication Disorders** - Dr. Joe Duffy, Mayo Clinic; **Counseling the Communicatively Impaired** - Dr. Lorraine Perlmutter, Albuquerque, New Mexico; **Professional Issues Related to Speech/Language Pathology and Audiology** - Betty Jane Phillips, ASHA and Dr. Charles Speakes, University of Minnesota; **Marketing in Audiology** - Dr. Daryll Teter, Denver; **Identification and Management of the Minimally Hearing Impaired Child** - Dr. Fred Bess, Vanderbilt University; **Humor in Therapy** - Candace Fancher, Gillette Children's Hospital, St. Paul.

The convention will also include contributed papers from MSHA members, a student forum, and a variety of exhibitors along with many other informative sessions. Contact Karlind Moller (612) 625-5945 or Jane Carlstrom (612) 624-3322 for registration materials and complete program. Non-member pre-registration is \$65 for the three-day convention.

### April 22-24, 1987

**"The Fortieth Annual Conference of the Presidents' Committee on Employment of the Handicapped"** will be held in Denver, Colorado, which is the first time that this event will be held outside of Washington, DC. This conference usually attracts 3,000 to 4,000 people. Seminars, workshops, a job fair, and exhibits will focus on the employment of people with disabilities. For more information, contact: Robert Ruffner, President's Committee on Employment of the Handicapped, Washington, DC 20036. Tel. (202) 653-5044.

## 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.

**On My Own: The Impact of Semi-independent Living Programs for Adults with Mental Retardation**, A.S. Halpern, D.W. Close, & D.J. Nelson, Paul H. Brookes Publishing Company, 1986. This book contains insights about semi-independent living programs as told by the adults who have experienced success as well as the pitfalls of such programs. The book presents an in-depth study and analysis of the lives of approximately 300 adults with mental retardation who live in over 30 semi-independent living programs in California, Colorado, Oregon, and Washington. Problems openly discussed include lack of leisure opportunities, unemployment, inadequate pay for staff, and retention of staff. In their final chapter, the authors propose an integrated systems model for improving research, service practices, policy formation, and evaluation of service outcomes.

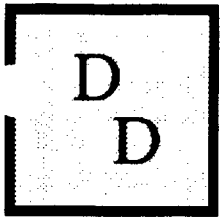
**New Perspectives on Down Syndrome**, S.M. Pueschel, C. Tingey, J.E. Rynders, A.C. Crocker, & D.M. Crutcher (Eds.), Paul H. Brookes Publishing Company, 1987. This book is the result of a state-of-the-art conference held in Boston, Massachusetts, April 23-25, 1985, sponsored by the Office of Special Education and Rehabilitative Services, in cooperation with the National Institute of Handicapped Research, and the 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.

**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*

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Vol. 12 No. 3  
March 1987

## METROPOLITAN COUNCIL DD PROGRAM NEWS

### 1987 AGENDA: INTEGRATION AND QUALITY

Historically this newsletter has provided readers with current information about resources and services in the field of developmental disabilities. The news items come from sources in Minnesota, other states and other countries. The disclaimer at the bottom of this page says that inclusion of information on any resource, service or product does not imply endorsement of them by the Metropolitan Council.

The same policy applies to this feature of the newsletter. When a program, study or set of principles is reprinted here, this does not mean that the Metropolitan Council is advancing any single way as the only legitimate or appropriate approach suitable for all individuals. However, because of the plethora of innovative activities and printed materials about developmental disabilities, one has to be selective. The basic criteria which have been used in selecting materials include: relevance for people with severe handicaps; consistency with the Council's DD policies, guidelines and criteria; experience/expertise of authors or developers of the materials and their practical use for consumers and practitioners in Minnesota.

This column will continue to feature innovative ideas. To some these will be considered controversial because they challenge long-held theories and current practices. They are not intended to threaten the "status-quo" but to guide and assist in its gradual improvement. Readers will learn about new options in services design and new visions of what quality of life can mean for persons who are developmentally disabled.

One vision of what could promote genuine integration and quality of life for persons who are developmentally disabled can be found in the *Metropolitan Council's Developmental Disabilities Regional Policy Plan* (1985). Another perspective of that vision can be found in the

recently published, *A New Way of Thinking* (1987), a policy briefing publication of the Minnesota Governor's Planning Council on Developmental Disabilities. The regional policy plan can be obtained from the Metropolitan Council by writing to the address listed on the masthead or by calling (612) 291-6464. *A New Way of Thinking* can be requested by writing or phoning the DD Program; State Planning Agency; 201 Capitol Square Building; St. Paul, MN 55101; (612) 296-4018.

The following article may also be helpful in improving current practices. It is reprinted from the *Information Exchange Bulletin*; Vol. 1, Number 5; September 1986. The bulletin is a publication of the G. Allan Roeher Institute - Kinsmen Building; 4700 Keele Street; Downsview, Ontario, M3J 1P3 Canada.

### Integration for People with Challenging Behaviors

The Community Integration Project (Center on Human Policy, Syracuse University) has recently prepared a paper entitled, *A Description of the Characteristics of Integrated Community-based Programs for People with Challenging Behaviors* (April 1986). Based on site visits and many telephone interviews with programs nominated as a result of a nationally advertised search, the following practices were consistently identified as crucial to living arrangements which support individuals with "behavior problems" to live in typical homes in the community:

- Commitment to integration (responsibility to resolve issues in a particular person's life within the community, no return to institutions);
- Ecological perspective of behavior (a particular behavior is seen as caused by the interaction of all the elements present in the environment in which it is exhibited, not as part of the person);
- Small settings (a person is more secure because of the need to relate to fewer people and has a greater sense of control of his or her environment);
- Small agencies (there's a greater possibility for

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.

everyone to continue to be directly involved with the people being served, and so develop a real sense of responsibility for and commitment to them);

- Heterogeneous groupings (the worst approach is to group people with challenging behaviors in one "behavioral house"; preferred alternatives are foster homes, apartments with service providers, or group situations where other residents do not have challenging behaviors);
- Individualization (individual service plans, the structuring of programs in response to the person, the place where a person lives is his or her home first and a human service setting second);
- Flexibility (response to the individual, flexible funding is especially important to meet individual need or short term crisis);
- Positive interventions (target on developing positive, socially valued behaviors which are either incompatible with the undesirable behavior or fulfill the need which the "problem" behavior expressed);
- Support services (an effective array of services which support the person and the residential provider--24 hour on-call crisis intervention and back-up, in-home behavioral consultants, respite, homemaker aides, in-home support staff for foster homes, and case management with caseloads small enough to ensure the manager's real involvement with the resident);
- Central role of the direct service provider ("front line" staff relate to professional consultants in a mutually supportive and interactive way rather than hierarchically).

## RESOURCES/SERVICES

### A New Guide for College-bound Students Who Are Hearing Impaired

*A Guide to Colleges for Hearing Impaired Students* has recently been published by Academic Press, Inc. The new guide provides a detailed overview of two- and four-year colleges in the U.S. that offer accredited programs and special services for hearing-impaired students. Information includes: college identification data; key contact persons who offer assistance, support and encouragement to the college student with special needs; majors offered; admission requirements; application deadlines; size of school enrollment; costs; modifications to traditional learning environments; and additional services offered. It also includes suggestions on what to look for in a college program, and what questions to ask. For more information, contact Karen Brogan, Academic Press Marketing Department, 6277 Sea Harbor Drive, Orlando, Florida 32821. Phone: (305) 345-2746.

### Free Assistance for Employers

For employers who want to hire persons with a

disability, here is a valuable resource:

- JAN - The Job Accommodation Network - a national information network and consulting service for employers who want to hire or retain qualified workers. It brings together information from many sources about practical ways of making accommodations for employees and applicants with disabilities.

JAN also enables employers to discuss with other employers accommodation solutions which they have implemented and proven successful. Accommodations usually are not expensive and JAN offers comprehensive information on methods and equipment that are available on a wide range of accommodations that have proven effective.

As a free service of the President's Committee on Employment of the Handicapped, JAN is available to any employer via a toll-free number: 1-800-JAN-PCEH. Callers can discuss their problems and information needs and get immediate suggestions on solutions from JAN's Human Factor Consultants. There are now 4,700 accommodation examples in the database, plus 2,000 items listed in the manufacturer file.

### Directory of Transition Services in Minnesota

PACER has developed an extensive directory programs and services in Minnesota for students in the transition years. The information is arranged by geographic area and type of program. Printed copies of the regional sections are available, or persons may call to receive information, (612) 827-2966 or 1-800-53PACER (parents of students with handicaps may call toll-free).

### 99th Congress Summary of Disability Legislation

*A Review of the 99th Congress: Disability-Related Legislation*, is available from the Minnesota State Council for the Handicapped. For a free copy, send a self-addressed envelope to: Wendy S. Brower; Minnesota State Council for the Handicapped; 208 Metro Square Building; 7th and Robert Streets; St. Paul, Minnesota 55101.

### REQUEST FOR ASSISTANCE

■ THE ASSOCIATION FOR RETARDED CITIZENS (ARC) MINNESOTA is seeking volunteers for the **Partnership for Quality Services** monitoring project. Funded through the Governor's Planning Council on Developmental Disabilities, the project is designed to ensure high quality lifestyles for persons with mental retardation through the use of citizen monitors. Community volunteers will visit programs throughout Minnesota that serve persons with disabilities to observe and evaluate the quality of services received. Training

will be provided, and volunteer citizen monitors will be asked to make a one-year commitment to allow three or four site visits. Partnership for Quality Services is a cooperative effort among parents, service providers, consumers and community members. For an application or more information, call Jean Swanson, Project Director; 827-5641 or toll-free in Minnesota 1-800-582-5256.

■ **TRANSITION PROJECT VOLUNTEERS** - Needed to take training (March 12 and 13) - can be parents, educators (who'd like to present PACER's "transitional needs" curriculum to their students), adult consumers, and interested others. Training will be provided by presenting a series of sessions about transition. The sessions for students are conducted in high school settings. Contact Christine Hunter or Kris Torma at (612) 827-2966.

■ **COUNT ME IN** - Volunteer puppeteers needed by PACER for an exciting and satisfying way to teach and work with young children. Mid-year enlistees will be provided with special, individualized training. Contact Becky Steeber or Cathy Milota at (612) 827-2966.

#### **ST. PAUL '87 LECTURE SERIES**

The Epilepsy Foundation of Minnesota is presenting a series focusing on epilepsy and related issues. The sessions are designed for persons who have epilepsy, their families and others who are interested. The next three sessions will be held at the St. Paul Room, Bethesda Lutheran Hospital, 559 Capitol Blvd., St. Paul, from 7-9 p.m. A donation is requested.

- April 6** **FILM: "SURPRISES OF FAILURE"**  
Focus: Achieving Success in the Face of Obstacles  
Speaker: Martha Benton, Employment Specialist TAPS
- May 4** **THE ISOLATION TRAP**  
Focus: How One Becomes Isolated; Steps to Break Out of the Isolation Trap; Resources  
Speaker: Faye Sleeper, Social Services Coordinator, People House
- June 1** **MANAGING MEDICAL EXPENSES**  
Focus: Financial Resources; Getting the Most from Your Insurance; Other Helpful Hints  
Speaker: Anne Barnwell, EFM

For more information: Logan Frederick; Epilepsy Foundation of Minnesota; 672 Transfer Rd.; St. Paul, MN 55114; (612) 646-8675

#### **FOCUS ON DISABLED BATTERED WOMEN**

The Disability Awareness Project under the Minnesota Coalition for Battered Women will sponsor two one-day statewide training workshops:

■ **April 14.** A workshop for the staffs and volunteers of Minnesota's 17 battered women's shelters will be held at the Earle Brown Center on the St. Paul campus of the University of Minnesota from 9 a.m. to 5 p.m. The workshop will focus on disabilities, abuse experiences of disabled women, and resource information exchange.

■ **May 15.** A workshop for disabled persons and organizations serving them will be held at the Ramada Hotel, I-94 and White Bear Av., St. Paul, from 9 a.m. to 5 p.m. Purpose will be to educate disabled persons as to their rights in an abusive situation.

For more information: Handicapped Organized Women (HOW); 1551 Ruth St.; St. Paul, MN 55119; (612) 222-6783 or 771-5216.

#### **MINISTRY TO DISABLED TO SPONSOR INTER-CHURCH EVENT**

The Association for Ministry to the Retarded, Inc. (AMR), will hold its annual Praise Celebration on Friday, April 3, at Messiah United Methodist Church, 17805 Hennepin County Rd. 6, in Plymouth, MN., from 7-9 p.m. Families, professionals and church-workers will all be encouraged concerning effective ways to respond to the spiritual needs of people with mental disabilities.

AMR was established in 1979, and presently provides Christian education and fellowship programs to more than 400 retarded individuals on a regular basis. The ministry's director, Don Anderson, will be on hand to offer help to church representatives regarding "special" ministries.

There is no admission charge, but the public is encouraged to call ahead for seating reservations (612) 498-8389. If you are unable to attend, but would like information, please write to: The Association for Ministry to the Retarded, Box 808, Wayzata, MN 55391.

#### **EDEN WOOD SUMMER PROGRAMS**

Eden Wood, operated by the Association for Retarded Citizens (ARC) of Hennepin County, is accepting registrations for summer camping and vacation programs for children and adults with mental retardation. Eden Wood offers day, residential, off-site and family camping experiences from June 14 - August 28, 1987.

Located on Birch Island Lake in Eden Prairie, Eden Wood is accredited through the American Camping Association and maintains high standards in health, safety and program content and implementation. It serves 40 people per week on site and maintains a high staff-to-participant ratio which assures emphasis on individual needs, interests, and strengths. Resident camp offerings include weekly theme programs such as Creative Arts, Sports and Health, Rest, Relaxation,

Recreation and Leisure Specialties. For children and youth, resident and day camp offerings are available with various integration options. Family camp is open to all members of a family who have a member with mental retardation.

Eden Wood off-site trip offerings include weekend canoe and backpack trips, week-long adventures in the Boundary Waters Canoe Area, lake cabin and state park vacations, recreational vehicle trips to the Black Hills, Wisconsin Dells, and Yellowstone Park, and an airplane trip to Chicago. Registration fills quickly, especially for the off-site trips. For more information on programs and registration, call Nancy Thysell or Tom Gode at (612) 874-6650. Camperships are available on an ability-to-pay, first-come, first-served basis.

### **ADVANTAGES AND DISADVANTAGES OF GUARDIANSHIP/CONSERVATORSHIP**

Guardianship/conservatorship results in either total or partial loss of rights and decision-making power for the person. This means that the individual's needs must be paramount in the decision to seek guardianship.

Guardianship/conservatorship, when used improperly, may result in a total denial of the rights of the person. For a person with slightly impaired decision-making skills, the loss of all of those rights might be unthinkable unless there is a demonstrated need for protection which is substantially more important for the welfare of the person than the loss of such rights.

In contrast, the loss of such rights for individuals with significantly impaired decision-making skills may involve no real loss since they would not actually be exercising these rights. Their need for protection may be much more important for their welfare than retention of legal capacity. A properly affirmative guardianship provides a means by which rights may be asserted.

Guardianship is not necessarily the solution to the problem. Before seeking guardianship/conservatorship you should be satisfied that there is a compelling reason which is in the best interest and welfare of the person and that the advantages clearly outweigh the disadvantages.

The above information was provided by Kay C. Hendrikson; Public Guardianship Administrator; Quality Assurance and Protective Services; Fourth Floor, Centennial Office Building; St. Paul, MN 55155.

### **RTB SEEKS 16 ADVISORY COMMITTEE MEMBERS**

The Regional Transit Board (RTB) currently has 16 openings on its Transportation Handicapped Advisory Committee (THAC). The purpose of THAC is to advise the RTB on management policies and implementation/planning issues concerning metropolitan transit services for the elderly, handicapped and others

with special transportation needs. THAC is composed of a chair and 20 individuals who represent persons who are elderly, persons who are handicapped, other users of special transportation services, transit service providers and appropriate agencies.

Those who wish to be considered for appointment to this committee can request an application form by calling the RTB at 292-8789 or writing to 270 Metro Square Building, St. Paul, MN 55101. The deadline for submitting applications is March 11.

### **FOR YOUR INFORMATION**

#### **DHS State MR/DD Plan Available**

*The Minnesota State Plan for Services to Persons with Mental Retardation and Related Conditions: January 15, 1987, to January 14, 1989* has just been made available. For a copy, write or call the Minnesota Department of Human Services; Mental Retardation Division; Centennial Office Building - Fourth Floor; St. Paul, MN 55155; (612) 296-2160.

#### **Supported Employment Project RFP**

The Minnesota Supported Employment Project has announced a Request for Proposals for conversion of facility-based services to community-based supported employment targeted for groups who have already made substantial efforts but need further assistance. A copy of the RFP may be obtained from the Minnesota Supported Employment Project; 390 N. Robert St., Fifth Floor; St. Paul, MN 55101; Tel. (612) 296-5629 or 1-800-328-9095. Deadline for submitting a proposal is April 20, 1987.

#### **Free Training in Integrated Early Education**

People who are interested in developing "integrated" early intervention programs may wish to contact Project Dakota Outreach. The project provides technical assistance to parents and professionals who are creating or expanding services to children with special needs from birth to age four. It is funded by the U.S. Department of Education.

Project staff will provide free training in your community, along with consultation and materials. Two- or three-day internships also will be available for service providers in rural areas. The project aims to help develop early intervention services that are supportive of families, are in least restrictive settings, and are tailored to meet the needs of the child, family, and community.

For further information, contact Linda Kjerland; Project Dakota; Dakota, Inc.; 680 O'Neill Drive; Eagan, MN 55121; (612) 455-2335.

## Free Catalog of Electronic Aids

Radio Shack has issued its first catalog geared specifically to people with disabilities. The 32-page publication is entitled *Selected Products for People with Special Needs*. The items featured are also available at most of the 7,000 Radio Shack outlets nationwide.

Many of the products are designed to aid persons with hearing or sight problems. Among the devices are phone flashers that light up when the telephone rings and oversized number buttons on the telephone instruments.

Free copies of the catalog may be obtained by writing Radio Shack; Circulation Department; 300 One Tandy Center; Fort Worth, TX 76102.

## Interest Survey for Writers with Disabilities

If you are a writer with a disability, The Loft would like to hear from you. The Loft is a literary center that provides classes, workshops, and award opportunities to help writers develop. The Loft facility is inaccessible at this time, but is committed to making programs available in accessible spaces for writers with disabilities. For a copy of the survey form, write to: Susan Broadhead; The Loft; 2301 Franklin Av. E.; Minneapolis, MN 55406.

## Jew Federal Funds for B-2 Education

A recently passed federal education amendment (PL 99-457, Part H, Handicapped Infants and Toddlers Program), authorizes new funding for providing services to children from birth through age two who are handicapped. Based on Minnesota's population of children under age two, the federal government has determined that about \$893,000 will be made available this year to Minnesota to develop services for children with disabilities in this age group.

These funds enable states to apply for federal grants to develop programs for children with disabilities age two and under. The law is an expansion of Public Law 94-142, the Education for All Handicapped Children Act. The new law mandates services at age three (already the case in Minnesota) and encourages services for younger children.

## Report Inaccessible Polling Sites

Readers are asked to help identify polling sites that were inaccessible during the last election. Please contact: Susan Lasoff; Minnesota State Council for the Handicapped; (612) 296-6785 or (toll-free) 1-800-652-9747.

## Interpreter Referral Changes Announced

The Minnesota Department of Human Services (DHS) and the Minnesota Foundation for Better Hearing and Speech (MFBHS) have agreed to embark on a new direction for providing statewide computerized interpreter referral services. The agreement calls for a year-long transitional period during which the Interpreter Referral Center (IRC) will coordinate all requests for interpreting services throughout Minnesota. DHS's Regional Service Centers for Hearing Impaired People (RSC) will provide the information and advocacy services related to communication accessibility and interpreting services in their areas.

To provide statewide interpreter referral services, MFBHS initiated a new "800" toll-free state number for calls originating outside of the metro area. The number is 1-800-652-9747 (voice or TDD). Callers will reach the state operator and must then request the Interpreter Referral Center. Callers inside the metro area should call 296-9299 (voice or TDD). TDD callers are asked to press the space bar several times in order to reach IRC.

## Minnesota Legislative Summary Newsletter

**Capitol Ideas**, a regular and current legislative newsletter published by the Minnesota State Council for the Handicapped, is available for a donation to help defray the printing and mailing costs. For subscription information: MSCH; 208 Metro Square Building; St. Paul, MN 55101; (612) 296-6785 or (toll-free) 1-800-652-9747 (voice and TDD).

## Scholarships/Financial Aid Available

The Alexander Graham Bell Association for the Deaf (AGB) announces Scholarship Awards for Profoundly Deaf Students attending college, 1987-88. Applicants must be prelingually deaf oral students. For details, contact the Scholarship Awards Committee; AGB Association for the Deaf; 3417 Volta Place NW; Washington, D.C. 20007-2778. Deadline is April 15.

The AGB Association for the Deaf also announces aid for elementary, junior or senior high oral deaf students who are mainstreamed in an independent or parochial school. Deadline is May 1. For details contact Financial Award Committee; AGB Association for the Deaf; 3417 Volta Place NW; Washington, D.C. 20007-2778.

## CONFERENCES/WORKSHOPS

### March 12-13, 1987

Minnesota Council for Exceptional Children annual conference, Minneapolis Plaza Hotel. Contact MCEC; 100 SE. 2nd St., #308; Minneapolis, MN 55414.

### March 14 and 21, 1987

"Parent Case Management Training" sponsored by the

Association for Retarded Citizens Suburban will be held both days from 8:30 a.m. to 3:30 p.m. at the Community Action Council, United Way Service Center, 14451 County Rd. 11, Burnsville, MN 55337. For more information: Marijo McBride; ARC Suburban; (612) 431-5000.

#### **April 9-11, 1987**

Minnesota Speech-Language-Hearing Association Annual Spring Convention, Sheraton Park Place Hotel, Minneapolis, MN. Contact Karind Moller (612) 625-5945 or Jane Carlstrom (612) 624-3322 at the Department of Communication Disorders; 115 Shevlin Hall; University of Minnesota, MN 55455 for registration materials.

### **FEDERAL HIGHLIGHTS**

The following articles are reprinted from *Word from Washington*, January 1987 issue published by the United Cerebral Palsy Associations. Some editing was done to maintain emphasis on DD-related issues.

#### **Medicaid Reform**

Medicaid funds now account for nearly one-third of all federal funds to states for services to persons with developmental disabilities. Because of the continued growth and cost of Medicaid, the 100th Congress will be exploring numerous legislative proposals to refocus Medicaid expenditures:

- Legislation to create a Medicaid block grant program which was introduced at the end of the 99th Congress is expected to be reintroduced by Senators Dave Durenberger (MN) and Daniel Evans (WA). The legislation probably will include state/federal changes in general Medicaid and Medicaid long-term care as proposed by the National Governor's Association.

- The issue of quality in Medicaid-assisted, long-term care facilities continues to be a priority of Representative Henry Waxman (CA). His staff is at work on redrafting H.R. 5450 introduced last year to incorporate the recommendations for nursing home reform which may include a set of expanded standards for persons receiving services in ICF/MR/DD long-term care facilities.

- The area of quality assurance is also a concern of Senator Lowell Weicker (CT). He may reintroduce his Quality Assurance for Disabled Individuals Act, S. 1948, which was introduced two years ago after hearings before the Subcommittee on the Handicapped revealed substantial abuse and life-threatening situations in state institutions. It is also possible that Senator Weicker's proposals may be included in legislation being drafted by Senator John Chafee (RI).

- Senator John Chafee's new legislation for long-term care Medicaid reform for individuals with developmental

disabilities is expected to be significantly different and an improvement over his previous bills. During the past several months, staff of six national advocacy/serv organizations have worked intensively to draft tentative specifications for legislation in this area including principles on quality assurance. These organizations will seek to remove the institutional bias of the Medicaid ICF/MR/DD program and to create a full array of individualized family/home/community living and support services. In order to achieve this necessary reform, the state counterparts of the national organizations will be calling upon persons with developmental disabilities and their families, relatives, friends, advocates and professionals during the spring and summer of this year to contact their Senators to support this essential legislation.

- At the administrative level, the Health Care Financing Administration (HCFA) now states that the long awaited final ICF/MR/DD standards will not be published until August of this year. Moreover, regulations have not been issued for most of the Omnibus Budget Reform Act provisions enacted in February 1986.

#### **Monitoring Last Year's Successes**

The major legislative victories achieved in 1986 require careful, persistent monitoring at the state and federal level in the months ahead. After a bill is signed into law by the President, the next step is for the appropriate federal agency to begin drafting regulations to further explain what must be done to implement the new law.

Proposed regulations are expected by March for both the Education of the Handicapped Amendments of 1986 (P.L. 99-457) and the Rehabilitation Act Amendments of 1986 (P.L. 99-506). The publication of the proposed regulations is followed by a public comment period which will then be followed by publication of final rules.

These laws as passed require more clarification concerning the early childhood initiative, supported employment, and rehabilitation engineering. At a state level, there is a complementary need to meet with top staff officials to offer assistance and explore their implementation plans or "rules."

A similar level of scrutiny is necessary to monitor implementation of the Handicapped Children's Protection Act (P.L. 99-372), the Air Carriers Access Act of 1986 (P.L. 99-435), and the Employment Opportunities for the Disabled Act (P.L. 99-643). It will take continuing commitment by advocates to ensure that the mandates of the 99th Congress, when implemented, become new opportunities for employment, education, and independence for thousands of individuals with disabilities across the country. You may write your member of Congress for copies of these new laws.



# INFORMATION EXCHANGE

STATE  
SUPPLEMENT

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## Developmental Disabilities Program

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Minnesota State Planning Agency

Roger Strand, *Editor*  
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Member of

National Association of  
Developmental Disabilities  
Councils

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March 1987

### PLAN FOR SERVICES TO PERSONS WITH MENTAL RETARDATION OR RELATED CONDITIONS SUBMITTED TO LEGISLATURE

As required by Minnesota law, Sandra S. Gardebring, Commissioner of the Department of Human Services (DHS), recently submitted a plan for the delivery and funding of residential, day, and support services to Minnesota's citizens with mental retardation or related conditions to the Minnesota Legislature. The plan summarizes the history of the major programs and services as well as describes the current status of these programs.

Basic values and methodologies are outlined in the section entitled System Design, and include: normalization; community integration; support, not supplant, the natural home; age appropriateness; and real jobs, real homes, and real schools. Consciously or unconsciously, it is stated in the plan, attitudes and values toward children and adults with developmental disabilities are reflected in the behavior and attitudes of caregivers, in the location, size, and appearance of the environment in which services are provided, and in the selection of tools or materials to be used in delivering those services. In addition, because of an unprecedented expansion of community-based services during the past 15 years, the plan emphasizes the need for improved coordination of services and assurance of quality. The plan outlines nine goal areas for this biennium:

■ **Staff Training**--DHS is proposing a legislative initiative which will supersede and standardize training requirements found in various rules governing services. This legislation would authorize the Department to establish minimum training requirements for newly hired case managers and direct care staff. Entry level training would be required prior to providing care to persons with developmental disabilities. Advanced training regarding special needs populations will be provided. In addition, DHS is committed to assuring that annual in-service training will be available to approximately 6,000 existing employees in both the public and private sector so that they are aware of advances in the field of developmental disabilities.

■ **External Monitoring**--DHS will be proposing legislation which would fund and authorize the creation of an external monitoring system, consisting of parents

and other volunteers to visit day and residential programs routinely and monitor overall environmental factors.

■ **ICFs/MR Bed Decertification**--Continued voluntary decertification of beds in Intermediate Care Facilities for Mentally Retarded is anticipated. When applying for renewal of the Home and Community-Based Services waiver under Title XIX, DHS will be requesting 400 waiver slots (places) to enable several counties and residential services providers to accomplish service conversions which will make available to their residents smaller, more normal living arrangements. No involuntary closures, except those that might occur due to negative licensing action or federal look-behind activities are planned.

■ **Expanding Community Capacity for People with Most Severe Disabilities**--DHS staff will be working with counties and community ICFs/MR to assist with physical plant and/or staffing modifications so that small facilities can assist with meeting the needs of all persons, even those with more severe disabilities, in order for such persons to live in settings that are more normal than those in which they currently reside.

■ **Home and Community-Based Waiver**--DHS will submit a request for renewal of the Title XIX Medicaid Home and Community-Based waiver to the federal government prior to April 1, 1987, which will expand services by 960 persons. Among several assurances, DHS plans to assist counties in reducing reliance on group home models by: encouraging alternatives such as family foster care and in-home support services; and assuring that supported employment initiatives are encouraged to enable client integration and development of greater independence in normalized work settings.

■ **Community Services Technical Assistance**--DHS will assist counties and service providers in areas such as case management, assessment, service planning, quality assurance, contracting, and cost effectiveness. These services will be provided by regional services specialists, central office staff, and through information dissemination.

■ **Nursing Homes**--In order to prevent or identify inappropriate placements of persons with mental retardation or related conditions into nursing homes, DHS has established special screening procedures. Additional funds have been requested to make available the appropriate alternative community services for

approximately 180 persons identified as being inappropriately placed in nursing homes.

■ **Division of Developmental Disabilities**--With the addition of related conditions to the Division's responsibilities (referring to the Division of Mental Retardation Services), and in keeping with similar actions taken in other states and at the federal level, DHS will request passage of legislation to change the name of the division to Division for Developmental Disabilities.

Copies of the complete plan, entitled Minnesota State Plan for Services to Persons with Mental Retardation and Related Conditions: January 15, 1987 to January 14, 1989, may be obtained by contacting: Minnesota Department of Human Services; Mental Retardation Services Division; Fourth Floor Centennial Office Building; 658 Cedar Street; St. Paul, MN 55155. Tel. (612) 297-1241.

### **PARTNERSHIP FOR QUALITY SERVICES PROJECT LAUNCHED**

A project called *Partnership for Quality Services*, administered by the Association for Retarded Citizens of Minnesota, will soon be demonstrating the use of volunteer monitoring committees throughout the state. This is one of several projects funded by the Governor's Planning Council on Developmental Disabilities last fall intended to improve and expand upon Minnesota's case management system. According to Jean Swanson, Project Director, the overall purpose of the project will be to demonstrate how professionals, parents, consumers and members of the community can work together to develop quality services and to assure that people with disabilities lead valued lives in the community.

Residential and day programs are presently monitored by a variety of state, federal, and local agencies, Swanson pointed out. However, she continued, the reliance on accreditation standards and licensing requirements has not resulted in quality services or a system that promotes quality of life, quality of services, self-sufficiency, integration, productivity, and independence. For example, to what extent does the person actually participate in community life? Does an individual's environment reflect personal tastes and preferences? Does each individual have opportunities to develop relationships with persons not paid to be with them? Does each program reflect a commitment to the personal growth of the individual? These crucial questions are seldom, if ever, addressed in formal evaluations such as licensure, Swanson commented.

Michigan has had volunteer monitoring committees operating since 1979. Gerald Provencal, Director of the Macomb-Oakland Regional Center, is convinced that the presence of community volunteers and parents has made the difference between what is viewed as a mere "dwelling" and what is felt to be someone's "home". "We just had our annual evaluation of our volunteer monitoring program," said Provencal, "and all came

away with the feeling that it's quite a bargain: it eases parents' fears about placement by personally being involved; the providers of services get a new perspective about their services at little or no cost; and the residents obtain an infusion of ideas from and opportunity to interact with others who live in their community."

Jean Swanson expressed her hopes that the Partnership for Quality Services Project will not only provide the opportunity to improve services, but will also present an exciting opportunity to sensitize and educate people, both professionals and community volunteers, to value-based issues and the application of the principle of normalization. The role of the volunteer monitors will be to listen to and observe people with disabilities where they work or live, and then to respond directly to the service providers. It will not be their job to rate facilities but rather to identify overall policy issues and to bring about change toward improvement in the quality of people's lives. Most important, Swanson concluded, I would hope that the volunteer monitors will reinforce the many positive features of Minnesota's services to persons with developmental disabilities.

More information about the project is available from: Jean Swanson, Project Director, Partnership for Quality Services, Association for Retarded Citizens of Minnesota, 3225 Lyndale Avenue South, Minneapolis, MN 55408. Tel. (612) 827-5641, or (800) 582-5256, toll free.

### **TASH TAKES STAND ON CRITICAL ISSUES**

At its annual meeting on November 5, 1986, in San Francisco, the Executive Board of the Association for Persons with Severe Disabilities (TASH) passed several resolutions which can have nationwide impact upon the quality of services for persons with disabilities. This article is the first of a series each month to share these resolutions in their entirety:

#### **Resolution on the Cessation of Intrusive Interventions**

In order to realize the goals and objectives of the Association for Persons with Severe Handicaps (TASH), including the right of each person who has severe handicaps to grow, develop, and enjoy life in integrated and normalized community environments, the following resolution is adopted:

Educational and other habilitative services must employ instructional and management strategies which are consistent with the right of each individual with severe handicaps to an effective treatment which does not compromise the equally important right to freedom from harm. This requires educational and habilitative procedures free from chemical restraint, aversive stimuli, environmental deprivation or exclusion from services;

Therefore, TASH calls for the cessation of the use of any treatment option which exhibits some or all of the following characteristics: (1) obvious signs of physical

pain experienced by the individual; (2) potential or actual side effects such as tissue damage, physical stress, severe physical or emotional stress, and/or death that would properly require the involvement of medical personnel; (3) dehumanization of persons with severe handicaps because the procedures are normally unacceptable for persons who do not have handicaps in community environment; (4) extreme ambivalence and discomfort by family, staff, and/or caregivers regarding the necessity of such extreme strategies or their own involvement in such interventions; and (5) obvious repulsion and/or stress felt by peers who do not have handicaps and community members who cannot reconcile extreme procedures with acceptable standard practice;

It is further resolved that TASH's resources and expertise be dedicated to the development, implementation, evaluation, dissemination, and advocacy of educational and management practices which are appropriate for use in integrated environments and which are consistent with the commitment to a high quality of life for individuals with severe handicaps. For more information, contact: TASH; 7010 Roosevelt Way, NE; Seattle, WA 98115.

## PUBLICATIONS

**You Can Do It! A Guide to Maryland's Services for Young Adults with Developmental Disabilities.** Maryland State Planning Council on Developmental Disabilities, 1986. This guide is written for young adults with disabilities who are preparing to leave school and enter the world of work, job training, and community living. The guide serves as an excellent example of what might be adapted to the informational needs of residents living here in Minnesota. The focus is on the whole person, how to set goals, and how to go about reaching those goals by using appropriate resources. Topics covered include: jobs, housing, learning, getting places, being an adult, Supplementary Security Income, human rights, and available services. For further information, contact: Catherine Raggio, Executive Director, Maryland Planning Council on Developmental Disabilities, 201 West Preston Street, Baltimore, MD 21201. Tel. (301) 225-5077.

**A Community-Based System for the Mentally Retarded: The ENCOR Experience.** K. Casey, J. McGee, J. Stark, and F. Menolascino, University of Nebraska Press, 1985. This book was recently reviewed by James Conroy in the *Journal of the Association for Persons with Severe Handicaps* (Winter 1986), pp. 316-317. Conroy highly recommends this book for persons concerned with service system design and quality issues. ENCOR is the acronym for the Eastern Nebraska Community Office of Mental Retardation. This book presents an historical and philosophical account, for the permanent record, of how and why a service system moved away from large scale segregation toward enriched, small, and more integrated models. According to Conroy, "It is the location of one of the earliest and most successful efforts to completely reform the

structure and content of a service system." Five principles are presented as corollaries of normalization: developmental model, continuity, specialization, integration, and dispersal.

**Competitive Employment Issues and Strategies**, F. R. Rusch (Ed.), Paul H. Brookes Publishing Co., 1986. This book can be used as a guide for designing and implementing programs that will result in competitive employment for persons with all types of disabilities. Focus is on providing proper training and support for workers instead of simply upon job placement. Lou Brown provided this summary, "Arranging for historically excluded people to perform real work in the real world for real pay is exciting, challenging, meaningful, and fun. . . . this text will challenge us all to think about new, different, better, and more community-oriented day-to-day approaches to training for employment." For more information, contact: Paul H. Brookes Publishing Co., P.O. Box 10624; Baltimore, MD 21285-0624. Tel. (612) 377-0883. (800) 638-3753

## CONFERENCES/WORKSHOPS

### MARCH 23, 1987

**Openness in Adoptions: Changing Needs, Changing Approaches** is a community forum about changes in adoption practice affecting birth parents, adopted persons and adoptive parents. The forum is sponsored by Children's Home Society of Minnesota and will be held at Lutheran Brotherhood Building, Minneapolis Auditorium, 625 Fourth Avenue, South, Minneapolis, Minnesota. For more information, contact: Children's Home Society of Minnesota, 2230 Como Avenue, St. Paul, MN 55108. (612) 646-6393.

### APRIL 2-3, 1987

The Sixth Annual Spring Conference of the Minnesota Association of Educators of the Mentally Handicapped and the Minnesota State Department of Education will be held at Breezy Point Resort. The theme of the conference is **New Ways of Educating Students with Mental Handicaps**. For more information, contact: Denny Martin; Washington School; 804 Oak St.; Brainerd, MN 56401. Tel. (218) 828-5221.

### MAY 14-15, 1987

**The Fourteenth Annual Issues in Mental Retardation Conference: Planning Normalized Futures**, will be held at the Earle Brown Continuing Education Center on the St. Paul Campus of the University of Minnesota. This conference will be co-sponsored by Continuing Education in Social Work at the University of Minnesota and Gillette Children's Hospital in St. Paul. "Personal Futures Planning" will be presented by Dorothy Skarnulis and Jane Wells. Other sessions will include consumer-owned housing, post-school transition, home-like qualities in housing, supported employment, enhanced self-esteem, and innovative applications of waived services. Fee: \$75.00. Contact: Neil Tift; Conference Services; Continuing Education in Social Work; 107 Armory Building; 15 Church Street, SE; Minneapolis, MN 55455-0139. Tel. (612) 625-3020.

## 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.**

**Ethics of Dealing with Persons with Severe Handicaps: Toward a Research Agenda**, P. R. Dokecki, & R. M. Zaner (Eds.), Paul H. Brookes Publishing Co., 1986. This book grew out of a conference on the ethics of intervention decision-making for persons with severe mental retardation, held in the spring of 1985 at the John F. Kennedy Center for Research on Education and Human Development, Vanderbilt University. Focusing upon the moral and practical issues in this book are ethicists, theologians, special educators, psychologists, physicians, and lawyers of national distinction. Central to discussion is the question, "Are all of today's actions in the best interests of individuals with disabilities?" A host of other questions are confronted, as well, e.g.: "Does a client have the right to discontinue habilitation?" "What rights to privacy and dignity do persons with handicaps have?" "What moral rights do persons with handicaps have?" These and many other issues demand public discussion. The authors suggest certain steps to be taken toward resolving these problems.

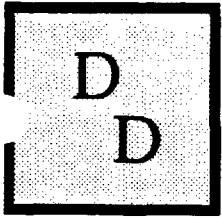
**Professional Self-Management: Techniques for Special Services Providers**, C. A. Maher (Ed.), Paul H. Brookes Publishing Co., 1985. This book is for everyone in human services, for it serves as a guide for improving self-management and personal growth. The individual chapters cover: time management, stress management, conflict management, professional development management, work relations management, authority management, personnel management, intervention management, and case management. According to the authors, the complexity, breadth, and scope of the daily work routine can be confusing even to the most experienced specialist. Professional self-management places a premium on learning as much as possible about yourself in relation to the work setting, as well as becoming adept at influencing that setting and your work routine.

**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

### 1987 AGENDA: INTEGRATION AND QUALITY

The recent publication from the Minnesota Governor's Planning Council on Developmental Disabilities is called, **A New Way of Thinking**. The title refers to the fact that we have learned a great deal of new and promising information about people who are developmentally disabled and that this knowledge is changing our actions.

The publication provides not only valuable data and information but also graphic accounts of how new approaches to services have made dramatic improvements in the quality of life for persons with severe, multiple handicaps. The publication is "must" reading for public officials, their administrative agencies at the state and local levels, for suppliers of services, for parents and for all citizens of Minnesota.

While there are many people totally unaware of this "new way of thinking" and others who are aware but resisting new approaches, there is a core of persons wanting assistance to make changes in their operations.

In the month since the publication was made available, there have been numerous conversations and requests for more direction on how to put the new principles into practice from parents and staff of residential facilities, DACs, rehabilitation facilities, social service agencies, advocacy organizations, etc. These people are seeking resources for staff orientation and continuing in-service training in how to plan and provide services: consistent with the new perspective.

New practices will flounder and fail unless families, supervisory personnel and those staff in daily, direct contact are provided with the rationale for change, and documentation that the newest principles and practice have succeeded with persons who are functionally and diagnostically similar to those they know and serve.

Families should not accept their offspring's past or current functions as a reliable indicator of what is possible. Staff must sometimes start with very basic elements of instructional technology, should also develop higher expectations and more open attitudes about the people with whom they work. There appears to be weighty evidence that our attitudes and lack of knowledge and skills have been more limiting than a person's disabilities.

But even if we accept the need for change, in order to meet its demands for parents and staff to get appropriate skills, we must accelerate all of our training resources. Colleges and universities who provide training for relevant professionals must be able to provide instruction in best professional practices and their conceptual foundations. Those charged with continuing education should gear up to provide workshops, classes and seminars explaining the principles that will lead to societal integration and futures of quality for people who are developmentally disabled. Regulatory agencies should review current standards and revise them where necessary to assure results consistent with goals of integration and lives of quality. Parents should recognize that attempts to improve services are not threatening to them or their children, but are being introduced to assist the children and the parents to better exercise their human and civil rights. Students in the many fields of developmental disabilities should know and seek what is entailed in good instructional programs. Policy makers should adapt policies consistent with best practices which are advanced on the basis of evidence.

Leadership programs that enable key professionals, parents, public officials and administrators to come together to learn about the new strategies should be offered. Direct care staff, both within a service sector and across service sectors, should be provided opportunities to network on both formal and informal bases to exchange ideas about common problems and solutions.

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.

It is recognized that the time to acquire this knowledge and training is very limited, but to by-pass such opportunities is difficult to defend. Recommended reading:

■ **Beyond the Ordinary: The Preparation of Professionals to Educate Severely and Profoundly Handicapped Persons.** Edited by Robert Perske and Judy Smith. 1977

■ *Leadership in Integration*, an article in **Entourage**, Volume 1, Number 4, Autumn 1986. A quarterly magazine "promoting community living for persons with a mental handicap" published by the G. Allan Roeher Institute; Kinsmen Building; 4700 Keele Street, Downsview, Ontario M3J 1P8. \$16 per year.

■ **Community-Based Curriculum: Instructional Strategies for Students with Severe Handicaps.** (See **Publications** for A review of this handbook.) These publications will be available from the Metropolitan Council's Curriculum Library in May.

### **Volunteer For The Legal Advocacy Quality Assurance Project**

Legal Advocacy has received a one-year federal grant from the Department of Health and Human Services to evaluate whether persons with the most severe disabilities are receiving quality residential and day program services designed to meet their individual needs. First a comprehensive Individual Habilitation Plan Review Form will be designed. Then the IHP Review Form will be used to review a minimum of 30 persons with severe disabilities in both their residential and day programs. Those reviews will be completed by a professional in the field. The evaluation will focus on both quality-of-life and state-of-the-art programmatic issues. If you know of someone who has a severe disability and could benefit from an IHP review, please have their guardian contact Carol Rydell at 332-1441 in the Twin Cities or 1-800-292-4150 toll-free.

Another task of the project is to train volunteer monitors to conduct IHP reviews. A second version of the IHP Review Form for non-professionals will be designed for that purpose. Jane Wells, who has extensive experience with PASS training, will design the training modules and conduct the training for the volunteers. The training will be particularly useful to parents and guardians of persons with a severe disability. If you know of someone who would be interested in this type of training, please have them call the project number.

At the end of the project year, a report summarizing the reviews and identifying systemic barriers to quality services will be completed and materials developed by the project will be disseminated to Protection and Advocacy Agencies, Developmental Disabilities Councils and University Affiliated Facilities around the country.

### **EMMA B. HOWE MEMORIAL FOUNDATION REVISES GUIDELINES**

The Emma B. Howe Memorial Foundation has revised guidelines for grant applications. The grant application process begins with a letter of inquiry to the foundation. The foundation staff will request a formal application if the request fits foundation guidelines. The next letter of inquiry deadline is June 10, 1987.

The new guidelines identify a specific focus. They state the foundation will consider applications from groups serving the poor and disadvantaged; children; persons with handicaps and those needing rehabilitation, and discrimination victims. In 1987, the foundation will focus on programs serving children from low-income families and their families.

Grants are made for one year, but the foundation will consider second year support following a program's positive annual review. Organizations applying for Emma Howe grants must be located and supply service in Minnesota; meet tax exempt designations, and be registered with the Minnesota Department of Commerce under the Charitable Solicitations Law.

Applicants eligibility has become more restricted than originally permitted. To be sure of eligibility criteria and to learn more about the specific types of application the foundation will consider write or call the foundation c/o The Minneapolis Foundation; 500 Foshay Tower; 821 Marquette Avenue; Minneapolis, MN 55402; (612) 339-7343.

### **RESOURCES/SERVICES**

#### **SignFont: An Alphabet For American Sign Language**

SignFont, a system created for writing ASL, released its first diskettes January 1987. This system allows materials written in ASL to be typeset for books, newspapers, and magazines. SignFont symbols for handshape, location, contact, movement, and non-manuals are written from left to right. When printed, a page of SignFont conveys the same amount of information as a page of written English. Instead of writing straight across a line as is done in English, SignFont will have five different levels to show the vertical location of a sign relative to the body. A complete description of the written system is available. Contact Jan Zimmerman, (619) 457-2526 (V) or (619) 457-1876 (TDD) for additional information.

#### **ARC St. Paul Education Programs**

Two programs for parents and professionals will be presented at the Arlington Hills Presbyterian Church, 1275 E. Magnolia, south of the intersection of Maryland Avenue and Johnson Parkway. Pre-registration is necessary. ARC St. Paul member registration fee is \$5 per session; non-members - \$8 per session. Call Mary

Hinze, ARC St. Paul, (612) 224-3301 to register.

**Friday, April 24: Family Owned Housing.** A new idea that can help create residential stability for people with mental retardation. Home ownership can be an option for anyone, regardless of the degree of disability. Many possibilities exist for ownership, location, staffing and financial support. The speakers who are exploring these alternatives for Minnesota are Bud Seltzer, parent, and Tom Field, Mental Retardation Division, Department of Human Services, 7-9 p.m.

**Saturday, May 2:** Tour a variety of residential programs in Ramsey County; meet residents and staff and hear about lifestyles in the 80's. Meet at the ARC office to pick up informational materials and spend the morning visiting. Limited to the first 12 who register. 9:30 a.m. to 12:30 p.m.

### **Free Speech and Language Screening and Free Orthopaedic Screening at Gillette Hospital**

A new free speech and language screening clinic will be held the first Thursday afternoon of every month at Gillette Children's Hospital, 200 East University Avenue, St. Paul. The screening clinic is for children up to age 18 who have difficulty with pronunciation, diction, vocabulary, or comprehension.

Parents, day-care providers, or school personnel who suspect a child may be delayed in speech and language development are encouraged to make an appointment. The screening, conducted by a certified speech and language pathologist, takes about 30 minutes. For information or to make an appointment, call Ginny Bruno at 291-2848, extension 234.

Gillette Children's Hospital also offers free orthopaedic screening for children up to age 21, with possible bone, joint or muscle problems every second Friday of each month. Parents or school personnel who suspect a child may have difficulty moving his or her arms, legs or back are encouraged to make an appointment. Call 291-2848, extension 147, for more information or to make an appointment for the orthopaedic screening.

### **Weekend Retreats for Mothers**

Mothers of a child or adult with mental retardation or developmental delay are invited to attend a Mothers Respite Retreat Weekend this spring, sponsored by Association for Retarded Citizens (ARC) of Hennepin County. Weekends are scheduled to bring together mothers of children of similar age and situation. April 10-12 is for mothers of a young adult or adult. May 8-10 is for mothers of an infant or toddler. Cost for the weekends is \$45, with financial assistance available for those in need. Site for the weekends is Eden Wood Camping & Retreat Center in Eden Prairie, operated by ARC. Further information and registration materials can be obtained by calling (612) 874-6650 or writing the

ARC Hennepin County; 2344 Nicollet Ave. So., #370; Minneapolis, MN 55404.

### **New Driver Education Courses at Courage Center**

Courage Center offers a specialized driver education program for people with special needs. The program is ideally suited to people with physical disabilities, mental or emotional impairments and other conditions who have the potential to drive or could benefit from being able to drive themselves.

The Courage Center Driver Education program is the most comprehensive service of its kind in the midwest and features:

- evaluation of driving potential and driving skills
- needs assessment and recommendations for special adaptive equipment
- individual tutoring for state permit test
- private behind-the-wheel instruction in specially equipped sedan, low effort van or low effort min-van
- use of equipped Courage Center vehicle for state road test
- off-the-road lessons on Doron driving simulator for new drivers.

The cost of Courage Center Driver Education services varies with the type and extent of service delivered. Services may be covered by DRS, Worker's Compensation, insurance and other funding. Fee adjustments may be requested if necessary. Courage Center will schedule an evaluation and/or lessons and can help with necessary authorization and billing arrangements. For information: Dave Nelson or Steve Quinn; Courage Center; 3915 Golden Valley Road; Golden Valley, MN 55422; (612) 588-0811.

### **PACER Supported Employment Workshop**

The last of the new PACER workshops on Supported Employment will be held on April 30, 1987 at the North Como Presbyterian Church, 965 Larpenteur Avenue West in St. Paul. Registration - 6:45 p.m. Workshop 7-10 p.m.

These information meetings will explain to parents, guardians, and to persons with disabilities able to learn in this setting, what our state's new supported work project is about and what it can mean for persons with handicaps. Supported employment is intended for persons with disabilities beyond school age for whom regular employment has traditionally been considered unlikely. Because of the severity of their disabilities, these people need intensive ongoing support to

perform in a work setting.

Supported employment programs can provide that necessary support. These programs allow people with severe disabilities to work among non-handicapped persons at regular job sites within the community. Supported employment is an exciting prospect, but raises many questions for those involved. This meeting may answer some of these questions, including those concerning Supplemental Security Income (SSI) and case management services. For more information: Cathy Urbain; PACER; 4826 Chicago Avenue South; Minneapolis, MN 55417-1055; (612) 827-2966.

#### **New Brochure on Supported Employment**

The Minnesota Supported Employment Project (MSEP) announces that new brochures are available for use as a marketing tool with potential employers and to assist persons who are developmentally disabled and their parents to understand this new service. To obtain the brochures contact MSEP. Let them know how you intend to use the brochures. MSEP; 390 North Robert Street, Fifth Floor; St. Paul, MN 55101; (612) 296-5629 or 1-800-328-9095.

#### **Expanded Respite Care Program**

The ARC Suburban's Respite Care Program has added several new providers recently. Currently there are fifteen providers available; ten in Dakota County, two in Hennepin and one each in Ramsey, Scott, and south Washington Counties. These people have indicated a willingness to provide respite care and have some background or training working with persons with disabilities. The list indicates providers' experience, training, availability, and whether they provide respite in their home or the family home. References and applications are available for the family. A family contacts a provider to make all arrangements including payment. To receive information about the program, call the ARC Suburban at (612) 413-3700.

#### **Peer Support Program**

The Metropolitan Center for Independent Living (MCIL) has thirteen trained persons available for support to others who are handicapped and wish for a greater degree of independence in their lives. The peer support group can be someone to talk with, to give you support in making decisions, to help find accessible recreation on a limited budget, to guide you through the transportation maze. For more information: Jackie or Rozanne, (612) 646-8342.

## **FOR YOUR INFORMATION**

### **Targeted Job Tax Credit Available**

The new Targeted Job Tax Credit law has been passed and went into effect, retroactive to January 1, 1986. The law allows businesses to receive a direct Federal Tax Credit for employing persons who are handicapped.

Employers can receive a 40% tax credit (not deduction) or up to \$2,400 for wages paid to individuals for their first year of employment. To realize this credit, the new worker must have a Job Services voucher and be kept on the payroll for a minimal time period, 90 days and 120 hours. For more information contact Bernice Koniar; Department of Jobs and Training; Rehabilitation Services; 390 N. Robert St., Fifth Floor; St. Paul, MN 55101; (612) 297-1649.

### **Residential Funds Available in Hennepin County**

The Association for Retarded Citizens (ARC) of Hennepin county would like to notify the community that it has available loan money to fund residential programs for people with mental retardation within Hennepin County. Two funds are available: Community Development Block Grant money is available for programs located within the City of Minneapolis, and ARC of Hennepin county Board Restricted money is available for programs located within Hennepin County. For further information regarding these funds and application procedures, please contact Ginny Gadbo Green at the ARC of Hennepin County office, at 874-6650.

### **Hennepin County Foster Care Sponsors Fun Run and 5K**

Hennepin County Foster Care is sponsoring a 5K and a Family Fun Run on Saturday, May 30th, at Lake Harriet in South Minneapolis. This is an event for every age. Pick your pace and enjoy. The one-mile family fun run starts at 9:00 a.m. near the bandstand. Runners will receive a button and a balloon. The cost is \$3.50 per person. Those wishing to register the day of the event should arrive at least one-half hour early.

For the more serious competitor, there is a 5K (3.1 mile) race that gives accurate time and placement. Awards will be given to men and women in each age class. The cost is \$6.50 per person. T-shirts are guaranteed to participants in both events who pre-register by May 15th. Wheelchair participants are welcome at both events. Registration forms are available at local sports shops and libraries. For more information, call Kathleen Holland at (612) 348-4270.

### **May 7 Is National Barrier Awareness Day**

St. Paul -- National Barrier Awareness Day is May 7. The



Minnesota State Council for the Handicapped urges all organizations, agencies or individuals throughout the state to develop their own formal plan of action to bring attention to National Barrier Awareness Day by creating a project which will make their community aware of the need for a barrier-free environment, whether those barriers are physical, or in programs or attitudes.

The Council has drafted a resolution for passage by the Minnesota House and Senate urging their support of "Access '92" which reaffirms their support of making all state owned and leased spaces accessible by 1992. Upon adoption, copies will be mailed to those who request them.

The Council plans to hold a press conference and rally at the Capitol on May 7 to report the progress of "Access '92" and the legislature's financial commitment to this project. Have representatives from your organizations be in attendance so that the legislature and public-at-large will understand the force behind the Council's commitment to "Access '92" and to totally barrier-free Minnesota environment. For planning packets regarding National Barrier Awareness Day, write to: National Barrier Awareness Day; 8507 Maryland Drive; Richmond, VA 23229 or call: 1-804-273-0070.

#### **PACER Second "Second City" Annual Benefit**

The audience response to the National Touring Company from Second City was so great that the improvisational theatre company from Chicago is being brought back to the Twin Cities to highlight this year's PACER benefit. Co-director Paula Goldberg said this week.

The type of comedy will be the same, she explained, but the material will be "brand new" for this year's performance, scheduled for Saturday night, May 9, at the Children's Theatre in Minneapolis. PACER uses proceeds from the ticket and auction purchases both to continue its COUNT ME IN handicap awareness programs for schoolchildren and to help handle the increasing number of calls from parents with questions or concerns about services for their children with all handicaps (physical, emotional, mental and learning). Ticket orders for the benefit evening, which includes the chance to bid on choice silent auction items, are already being taken by PACER. Seats will be assigned on a "first received, first choice" basis. To receive ticket order forms, contact PACER at 827-2966 or use its toll free number (1-800-53PACER) if you're a Minnesota parent and calling long distance.

#### **Family Lecture Series**

The Association for Retarded Citizens Hennepin County and West Hennepin Community Center are co-sponsoring a new lecture series for parents of children with developmental delay or disabilities:

- **April 22 - "Tools for Enriching Marriage"**
- **April 29 - "Enhancing Parent-Child Relationships"**
- **May 4 - "Letting Go"**

The three session fee is \$15 or \$10 for ARC members. The series will be presented at the Richfield Community Center; 7000 Nicollet Avenue South; Richfield, MN 55423 from 7:30-9 p.m. To register or for more information: ARC Hennepin County, 2344 Nicollet Ave., Suite 370; Minneapolis, MN 55404; (612) 874-6650. Scholarships are available for families unable to pay.

#### **Spring Quarter Classes**

*Skills for Life* is a special education program for adults to help them develop independent living skills, offered by Pillsbury House; 3501 Chicago Avenue, S.; Minneapolis, MN 55407. This agency offers many classes in the areas of home skills, community skills, and personal and physical development. All classes are free and held in the evenings. There are also special recreational events throughout the quarter. Feel free to call for more information or if you'd like to receive a newsletter regularly. (612) 824-0708.

#### **RECREATION/LEISURE**

##### **Linking for Leisure Pursuits**

Leisure Connections is a new program sponsored by ARC of Hennepin County. Actually, it is a restructuring of the Partners in Friendship program. Leisure Connections is a one-to-one peer leisure tutoring program in which a volunteer and a person with mental retardation are matched for participation together in a time-limited leisure program that is based at some community recreation site like the YMCA, community education or park and recreation departments. Through involvement in Leisure Connections, people with and without mental retardation will have opportunities to learn new things and make new friends. The program addresses the need for social support in community leisure opportunities for people with mental retardation. Participants in Leisure Connections are matched with regard to gender, age, leisure interests, residence proximity and time availability. To become involved in this program or for more information, please call Nancy Thysell at (612) 874-6650.

##### **Adaptive Recreation Happenings in St. Paul**

An attractive new newsletter for St. Paul residents who are handicapped is now made available as a joint effort between the St. Paul Public Schools (Community Education Department) and the City of St. Paul (Division of Parks and Recreation). The newsletter features an exciting array of adaptive recreation and leisure time

activities for persons who are mentally or physically handicapped. To receive a copy of the action for spring call (612) 298-5500 and request **Adaptive Recreation Community Happenings**.

### **Cable Program Entertainment/St. Paul**

Tune in cable station 37 Saturday evenings from 8:30 to 9:00 to watch MuSign. MuSign is a company of hearing and hearing impaired performers who choreograph and perform popular songs. Through a combination of dance, mime and ASL sign language they convey or "interpret" songs.

### **Camping and Travel Program**

Camp Friendship is located on Clearwater Lake, just 60 miles northwest of the Twin Cities Metropolitan Area. The 80 acres of natural woodland provide the ideal setting for an enjoyable and relaxing vacation. Camp Friendship offers both a summer and winter residential camp in which the participants get involved with learning new skills, participate in challenging and adventuresome activities, make decisions, meet new people, renew old friendships, and have fun. Camp Friendship also offers a travel camp program called VENTURES. VENTURES enables participants to enjoy and explore different parts of Minnesota as well as other areas of the United States including Orlando, Florida and Black Hills of South Dakota. Other Camp Friendship services include: Respite Care, Family Weekends, Specialty Weekends, and Facility Rentals. For information: Camp Friendship; Route 3, Box 162; Annandale, MN 55302; (612) 274-8376.

### **CONFERENCES/WORKSHOPS**

#### **April 6-7, 1987**

*A Wise Strategy: Employing Persons with Disabilities* is a workshop for personnel from business and industry, community service agencies, and public schools. It will be held at the Radisson University Hotel in Minneapolis. The purpose of the workshop is to enhance the transition of persons with disabilities from postsecondary nonvocational training programs to gainful employment in related career areas. This workshop is the product of a three-year federally funded project at the University of Minnesota and the University of Washington. Cost: \$45.00. For more information, contact: Joe Watruba, University of Minnesota, Room 460, VoTech Building; St. Paul, MN 55108. Tel. (612) 624-1214.

#### **April 9-10, 1987**

*Designs for Progress* is the theme of the 1987 Spring Training Conference of the Minnesota Developmental Achievement Center Association. It will be held at the Radisson Arrowwood in Alexandria, Minnesota. For more information, contact: MnDACA; 1821 University Avenue,

S-277; St. Paul, MN 55104. Tel. (612) 647-9200.

*Developing Leisure and Recreation Skills in Persons Who Have Developmental Disabilities* is a workshop sponsored by Government Training Service that will feature Stuart J. Schleien, Ph.D., workshop leader. The workshop will be held on the following dates and at the following locations:

**April 24, 1987--**Sheraton Inn Northwest, I-94 and Highway 169, Brooklyn Park, MN.

**June 1, 1987--**Radisson Arrowwood, Alexandria, MN.

Cost: \$40.00. For further information, contact: Mary Sabatke; Government Training Service; 202 Minnesota Bldg; 46 East Fourth Street; St. Paul, MN 55101. Tel. (612) 222-7409, or (800) 652-9719 toll free.

#### **April 25, 1987**

#### **8th Annual Metro-wide Consumer Conference.**

This year the consumer conference will be held from 11:00 a.m. to 10:00 p.m. at North East Metro-Tech in White Bear Lake. The theme for the conference will be *Reaching for Independence* with Sally Reardon of So. St. Paul, Irving Martin of St. Paul and Cliff Poetz of Minneapolis featured as keynote speakers. The conference is designed for persons with mental retardation who want to learn more about subjects of interest to them.

#### **April 27, 1987**

*Facilitating Integration at a Youth-Serving Community Recreation Agency.* Sponsored by the Jewish Community Center of St. Paul, 1375 St. Paul Avenue, St. Paul, MN 55116. The workshop will be held from 8:30 a.m. to 4:30 p.m. and will emphasize practical strategies for managing challenging behaviors and for integration. Fee is \$18.00 and includes breakfast and lunch. Registration by April 13, 1987. Call Linda Heyne at (612) 698-0751 for additional information about the program and overnight accommodations.

#### **May 2, 1987**

*Using Computers to Teach Language Skills to Young Children.* A professional's workshop sponsored by and at Courage Center; 3915 Golden Valley Road; Golden Valley, MN 55422. Speaker: Dr. Laura Meyers, research linguist at the City of Hope, California. Registration fee is \$50; deadline for registration is April 15, 1987. For more information (612) 588-0811, extension 147.

#### **May 7-8, 1987**

*Cerebral Palsy: Transition to Independent Living* Presented by the Continuing Education Committee of

the American Academy for Cerebral Palsy and Developmental Medicine. Holiday Inn-Nicollet Avenue, Minneapolis. Credits/CEO's available. Registration fees based on professional category: \$50-\$100. For information AACPDM; PO Box 11083; Richmond, VA 23230. Hotel reservations directly to Holiday Inn, Minneapolis, (612) 332-0337.

**May 11-12, 1987**

*Disability Policy: The State of the Nation* is a conference for people concerned about policies for persons with disabilities. It will be held at the Capitol Hill Hotel--Quality Inn, Washington, DC. Senator Lowell Weicker will serve as the keynote speaker. For more information, contact: Ms. June Webb; University of Maryland; Department of Special Education; Benjamin Building; College Park; MD 20742. Tel. (301) 454-8718.

## **PUBLICATIONS**

**Community-Based Curriculum; Instructional Strategies for Students with Severe Handicaps.** Mary Falvey. 1986. \$19.95. Paul H. Brookes Publishing Co.; P.O. Box 10624; Baltimore, Maryland 21285-0624. Dr. Falvey is on the faculty of California State University, Los Angeles, Division of Special Education. The book has value for professionals as well as parents concerned with developing ways to provide education that is community referenced. It is important to note that the premises and techniques suggested in the book are based on research findings, other publications, and direct experience and research conducted by Dr. Falvey and other contributors to the book.

The book's introduction covers a historical review of services and rights of individuals who are severely handicapped with a focus on the resulting environments. The chapter on assessment includes a discussion of strategies according to state of the art principles. It provides detailed instructions about how to determine the skills of individuals participating in chronological age appropriate and functional activities and how to collect data in the endeavor. The chapter on Instructional Strategies delineates preferred techniques and an example of that technique. Community Skills, Chapter 4, offers a rationale and discussion on developing and implementing community-based educational programs. The usual barriers to using community environments are listed with ways to overcome the barriers. Remaining chapters discuss strategies for parent-educator initiatives, for recreation-leisure skill development, for dealing with physical handicaps that may seem to inhibit students' functioning in community environment and for developing communications and other functional academic skills. The final chapter focuses on integration issues and strategies.

Dr. Falvey's strategies have relevance beyond the education setting and the student years. Strategies such

as peer tutoring for students can be transformed into "mentoring," an accepted method for one adult to provide guidance, assistance or support to another adult.

Ecological inventories of the adult's environment using the student inventory technique can produce the information needed for an adult to participate in a community event or activity with others who are not handicapped. The book provides practical instructions based on best professional practice.

## **Infants Can't Wait: National Center Calls for Action on Behalf of Our Nation's Children**

The National Center for Clinical Infant Program in Washington, DC, recently released a two-volume report calling for two major initiatives, and includes strategies for their implementation. **Infants Can't Wait** and its companion data book, **Infants Can't Wait: The Numbers**, review the developmental tasks and needs of infants and toddlers, describe the support for healthy development currently available in this country, and document needs which are not being met.

The first initiative recommended is the establishment of a basic floor of integrated services which would include: preventive health care; a level of economic well-being necessary for basic health and development; family social support services; and daily care for all infants and toddlers which recognizes their need for ongoing daily experiences facilitating their emotional and cognitive development.

In addition, the Center recommended an expansion of comprehensive, integrated services for infants and toddlers with special health and developmental problems or disabling conditions and for their families.

Separate, one-page fliers accompany the publications which outline aggressive activities at each level--local public and private action, state action, and federal action.

Highlighted in these reports is the following observation:

A wealth of new knowledge about the earliest years of life tells us some important things about infants.

- Infants learn, respond, and interact from the earliest moments of their lives.
- Infants are even more vulnerable than older children to emotional and social deprivation, as well as to physical injury.
- Development in the early years is too important to leave to chance.

Copies of these reports may be purchased by sending a

check for \$6.50 to: National Center for Clinical Infant Programs, 733 Fifteenth Street, NW; Washington, DC 20005. Tel. (202) 347-0308.

**You Can Do It! A Guide to Maryland's Services for Young Adults with Developmental Disabilities**, Maryland State Planning Council on Developmental Disabilities, 1987. This is a book written and designed specifically for young persons who are leaving special education and entering the world of work and community living. Although contents relate to the state of Maryland, it could easily be adapted to include similar resources in Minnesota, e.g., jobs, housing, learning, getting places (transportation and mobility), being an adult, Supplementary Security Income, human rights, and services. A free copy may be obtained by contacting: Catherine A. Raggio; Executive Director; Maryland State Planning Council on Developmental Disability; 201 West Preston Street; Baltimore, MD 21201. Tel. (301) 225-5077.

## **FEDERAL HIGHLIGHTS**

### **President's Budget Cutbacks in Disability Programs**

President Reagan's 1988 budget reduces funding for persons with disabilities. Special education would lose \$253.7 million, including \$224 million for grants to states for school age children, youth and pre-school children with handicaps. In explaining these cuts, Secretary of Education William Bennett called them necessary because Congress "spent too much" in 1987.

In addition to reducing the 1987 funds for special education state grants, the Department of Education has determined \$50 million appropriated by Congress for the new early childhood services was "unwarranted" and has identified it for extinction with a request of no money to fund the program in 1988. Other special education programs that would be cut: deaf-blind discretionary programs, early childhood planning, development, and implementation grants, and personnel preparation.

For rehabilitation services, the Department reduced funding for Vocational Rehabilitation State Grants, rehabilitation personnel training, and program evaluation. Also "unwarranted," according to the Department, is the new formula grant to the states for supported employment that became a part of the Rehabilitation Act last year. In the Department budget explanation the program was described as "unjustified in light of the Department's continuing efforts in this area...Formula grant assistance is not appropriate since states have just begun to test and develop approaches to conduct supported employment activities." Other programs funded by RSA with the exception of recreation, which was zeroed out, would be at the 1987 level.

Finally, under the President's Budget, beginning in 1988 the Department of Education would no longer provide

categorical funding for Vocational Education. This request is based on the premise that state and local government, the Department of Labor, and private corporations are the appropriate funding source for these training programs.

From the Department of Health and Human Services comes a request to cap Medicaid expenditures. The cap would draw the line at \$25.4 billion, which is \$1.3 billion less than the current spending projection for fiscal year 1988. Future year increases would be the Medical Care Component of the consumer Price Index.

Maternal and Child Health Block Grant funds would be frozen at the 1987 level. A new program would have MCH provide comprehensive case management services to pregnant women, including those who are at high risk of having low birth weight children, and pregnant teenagers.

Developmental Disabilities, a separate program in years past under the Health and Human Services Social Services Discretionary Programs, is placed with a "generic group" of 26 previous line item social service programs to "simplify the budget process and to focus resource allocation decisions on the over-all direction of Federal policy..." The total requested for these programs is \$34 million less than 1987. Priority for this money would be given to Head Start, Child Welfare, Aging Nutrition, Developmental Disabilities and Native Americans.

# INFORMATION EXCHANGE

STATE  
SUPPLEMENT

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Developmental Disabilities

Councils

April 1987

## PROGRESS AGAINST AUTISM CLAIMED BY DR. IVAR LOVAAS AT U.C.L.A.

Appearing in **The New York Times** (March 10, 1987), Daniel Goleman reported remarkable progress being made in the treatment of children with autism. Goleman had discovered the results of a study in the current **Journal of Clinical and Consulting Psychology**, written by Dr. Ivar Lovaas, research psychologist and director of the study at the University of California at Los Angeles.

Using a behavioral approach which emphasizes the training of parents at home, 19 children with autism were treated for up to six years in the program. Nine of these children were able to enter the first grade and blend into classes with other children who did not have a developmental disability, a success rate of close to 50 percent. Eight other children attended special classes for children with language problems in regular schools. Only two needed to be in classes with other children with autism.

Lovaas was quoted in the article as saying, "If you met them now that they are teenagers, you would never know that anything had been wrong with them. For instance, one now has an I.Q. of 130 and hopes to study meteorology at the Air Force Academy."

Critical to the treatment provided at U.C.L.A. is the opportunity to have contact with other children. Usually started by age 3, each child received 40 hours per week of intensive treatment by specialists trained in techniques of behavior modification. Treatment was continued by the child's parents at home and by teachers in preschool programs. During the first year, the aim was to get the children to stop their more bizarre and disruptive behavior, make contact with other people and begin to imitate what they saw others do. The second year emphasized helping the children to learn to talk and play with other children.

The children who made enough progress were enrolled in ordinary kindergarten classes. To avoid stigmatizing the children, the researchers did not inform the schools that the children had been diagnosed as autistic. The successes in the program were all among these children, who were promoted along with their classmates.

"If we had to admit that the child had a problem," said

Lovaas, "we'd say that it was 'language delay.' To prevent suspicion, we changed our name from Autism Clinic to Clinic for the Behavioral Treatment of Children."

Imitating and learning from normal children is crucial to the progress and to the successful treatment of children with autism, said Lovaas. He concluded, "It's the kiss of death to be in a class with other autistic kids. You won't learn anything useful."

## RADISSON UNIVERSITY HOTEL RECEIVES NATIONAL EMPLOYMENT AWARD

The Administration on Developmental Disabilities of the Department of Health and Human Services in Washington, D.C. recently selected six businesses throughout the United States for receiving an award in recognition of their outstanding contributions in the area of employment for youth and adults with developmental disabilities. The Radisson University Hotel in Minneapolis was one of the recipients of this national honor.

The award was presented by Acting Commissioner Casimer R. Wichlacz, who presented the awards at a National Forum held in New Orleans, Louisiana, March 11-14, 1987. He pointed out the noteworthy fact that the Radisson University Hotel had only recently opened on the campus of the University of Minnesota in March 1985. Since its opening, he said, Dianne Unwin, Personnel Director at the Radisson, has been extremely receptive to employment of persons who have developmental disabilities. The Radisson employs six persons with disabilities directly and contracts with community supported employment agencies for work crews of 12 to 15 persons to do specific jobs. The Radisson also allows Minneapolis and St. Paul schools to use the hotel as a training site for students who are disabled.

In addition, Wichlacz emphasized the benefits realized by the Radisson University Hotel, as reflected by testimony provided by Unwin: "It has been our experience at the Radisson that employees with disabilities have fewer absences, are on time, and in many ways are models for other employees."

## ST. PAUL YOUTH RECEIVES NATIONAL VOLUNTEER AWARD

On March 12, 1987, Molly Maurer, a student at Humboldt High School in St. Paul, received an Outstanding Volunteer Award from Acting Commissioner Cassner R. Wichlacz of the Administration on Developmental Disabilities (ADD) of the Department of Health and Human Services at the ADD National Forum held in New Orleans, Louisiana. The emphasis of the Annual Awards this year was to give recognition to America's youth who have made outstanding contributions as volunteers on behalf of persons with developmental disabilities.

Molly, who was nominated by a teacher at Humboldt for the award, is an extremely independent individual. Although her coursework has frequently been interrupted due to complications associated with Spina Bifida, she manages to find time to do the housework at home, help her father who had a debilitating stroke last year, visit her mother who has Multiple Sclerosis and resides in a nearby nursing home, and do volunteer work at both the Gillette Children's Hospital and the St. Paul Children's Hospital. Molly has done volunteer work for the past six years. At Gillette, she has worked in the Recreation unit playing games with the patients, and in the Public Relations unit, answering phones. At the St. Paul Children's Hospital, Molly worked in the Public Relations Department helping to distribute a weekly newsletter and answering phones.

According to her teacher, "Molly has always been extremely generous with her time in order to assist others whenever possible. Her positive outlook and the ability to 'keep going' against all odds serve as an inspiration to all of us. She is an excellent role model for other students with physical disabilities, as well as for those of us who are presently non-handicapped."

## NEBRASKA SUPREME COURT ISSUES OPINION IN DISCRIMINATION CASE OF FORMER MINNESOTA MAN WITH EPILEPSY

On February 20, 1987, acting upon an appeal from the District Court for Douglas County in Nebraska, the Supreme Court of Nebraska affirmed the lower court's opinion in the Case of **Father Flanagan's Boys' Home (Appellee) v. Goerke (Appellant)**. Danny Goerke, a former Minnesota resident, had filed a charge with the Nebraska Equal Opportunity Commission claiming discrimination against Father Flanagan's Boys' Home where he had been dismissed from employment as an assistant teacher because of his epilepsy. The Commission determined that the home had unlawfully discriminated against Goerke and ordered that he be reinstated to his former employment and be paid back wages and benefits. On appeal by the home, the District Court reversed the Commission's decision.

Danny Goerke, who had first experienced a grand mal seizure at age seven, had been seizure-free with the use

of medications for the past ten years. In 1983, when Goerke applied for work as an assistant family teacher at Father Flanagan's Boys' Home, Goerke stated in his written application for employment that he had a physical handicap which would impair his ability to perform the job. Goerke had had a Minnesota driver's license since age 16. He had previously worked for six months at Thistledeew, a juvenile correction facility for 12- to 18-year-old boys, operated by the State of Minnesota where he was required to do a considerable amount of driving, including transporting juveniles. The position of assistant teacher at Father Flanagan's Home also required transporting of residents.

Goerke was discharged from his employment at the home near the end of his training period and before he had driven any of the boys anywhere. The discharge came about after he asked the Family Couple to whom he had been assigned where he might store his medication, thus revealing the fact that he had epilepsy. The Home's policy (not written) was described as a "blanket exclusion for all individuals who had a known history of seizures."

One conclusion stated by the majority of judges was, "The fact Goerke has not yet had a seizure while transporting others does not require the Home to risk the safety of the boys in its charge on the basis of trial and error, and thereby invite and await disastrous results." They also noted that the U.S. Department of Transportation regulation disqualifies persons with epilepsy from operating motor carriers in interstate commerce and that in this case the safety concerns were similar. The conclusion they reached, therefore, was that Goerke's epilepsy was not unrelated to his ability to engage in the Home's occupation of assistant teacher and that the nature of epilepsy is such as to reasonably preclude performance of that employment.

Two minority, dissenting Nebraska Supreme Court Judges noted that through the Nebraska Fair Employment Practice Act, the Legislature had sought to secure to persons with disabilities full and equal access to employment, based on merit and bounded only by the actual disability which an employee or potential employee may be unable to overcome. Employment discrimination, attributable to a classification based solely on an individual's disability rather than ability, is "peculiarly repugnant in a society that prides itself on judging each individual by his or her merits," they stated. A disability, by itself, is not a permissible basis to assume that an individual is unable to function in a particular context, they also noted.

The dissenting judges continued:

Whatever has prompted the majority to refer to regulations of the U.S. Department of Transportation--regulations which the majority readily acknowledges are inapplicable to Boys' Town--remains without suitable explanation and cogent correlation. The federal regulations pertain to drivers of 18-wheelers, semis, tremendous trucks,

and other motorized mammoths moving for protracted periods as common carriers in interstate commerce. The undeniable differences between commercial interstate driving and Goerke's driving duties at Boys' Town annihilate any possible relevance regarding those federal regulations which, in relation to this case, are reduced to bureaucratic bunkum.

The majority's opinion apocalyptically announces: "The fact that Goerke has not yet had a seizure while transporting others does not require the home to risk the safety of the boys in its charge on the basis of trial and error, and thereby invite and await disastrous results." To the majority, it is absolutely inevitable that Goerke, an epileptic, will cause "disastrous results" in employment such as that at Boys' Town. The facts do not warrant such awesome augury. Only a conclusion contradictory to the prognostication of the majority is deducible from facts presented to this court.

One objective of the antidiscrimination provision of the Nebraska Fair Employment Practice Act is prohibition of employment discrimination resulting from unfounded stereotyping of persons disabled by some physical or mental handicap. That objective is, as yet, unrealized. Today, epileptics; tomorrow, diabetics; thereafter . . . ?

Copies of the Opinion of the Supreme Court of Nebraska in **Father Flanagan's Boys' Home v. Goerke** may be obtained from: Governor's Planning Council on Developmental Disabilities; 201 Capitol Square Building; 550 Cedar Street; St. Paul, MN 55101. Tel. (612) 296-4018.

## **TASH TAKES A STAND ON DEINSTITUTIONALIZATION**

On November 5, 1986, in San Francisco, the Executive Board of the Association for Persons with Severe Disabilities (TASH) passed several resolutions which can have nationwide impact upon the quality of services for persons with disabilities. This article is the second in a series to share the TASH resolutions in their entirety:

### **Deinstitutionalization Policy**

The Association for Persons with Severe Handicaps believes that a mutual consideration for both quality services and quality of life are necessary, and that this mutual consideration cannot be achieved in environments which segregate persons with disabilities from the community. Thus, TASH calls for the termination of services, activities, and environments which: (a) remove children from their homes and neighborhoods, and citizens from their home communities; (b) require that persons with disabilities live under circumstances that would not be considered acceptable for persons within that same age range were they not disabled, including institutions and large scale group homes and ICFs/MR; (c) rely exclusively upon paid caregiver and other professionalized relationships to

the detriment of more normalized social support networks, family systems, peer relationships, and friendships; and (d) stigmatize persons with disabilities by portraying them as individuals in need of help, care, and sympathy rather than dignity, respect, mutual companionship, and enjoyment.

TASH believes that both the commitment and the technology now exist to achieve alternative, truly community-based services. TASH calls upon the professional and advocacy community to work toward community-based options that reflect the full range of choices that are available to persons without disabilities. These choices minimally include:

- (1) the right to live in normalized, community-based homes, including living with parents, self-selected roommates, and varied groupings and environments considered desirable, appropriate, and chosen by persons without disabilities at particular ages in their lives;
- (2) the right to attend the same school he or she would attend if s/he did not have a disability and to receive at that school the individualized educational services which are appropriate for his or her needs without compromise to their development of interactions with peers (whether or not those peers themselves have a disability) throughout the school years;
- (3) the right of access to a variety of vocational training opportunities which allow for daily interactions with coworkers, employers, and (where relevant) consumers who do not have disabilities regardless of level or type of disability;
- (4) the right to participate in the kinds of extracurricular, recreational, and other leisure experiences enjoyed by typical peers and citizens; and
- (5) the right to daily and longitudinal social interactions with peers and other citizens (without regard to disability) that are oriented toward developing a variety of relationships, social support networks, friendships, and the ultimate goal of a normalized social status for individuals with disabilities.

Further, TASH supports the expenditure of government funds in support of families pursuing community integration.

For more information, contact: TASH; 7010 Roosevelt Way, NE; Seattle, WA 98115.

## 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.**

**Breaking Barriers: How Children and Adults with Severe Handicaps Can Access the World through Simple Technology**, J. Levin & L. Scherfenberg, ABLENET, Minneapolis, 1987. This is a resource guide for parents, teachers, and therapists who want to learn more about the functional applications of simple technology in home, school, and work settings. The guide illustrates how the use of automated learning devices (ALDs), one form of simple technology, can help persons with handicaps to access new experiences, new activities, and new environments. ALDs can allow the user to independently control electrical appliances or battery-operated toys. A variety of activities and resources are provided, all of which are geared to encourage active participation, success, and independence by children and adults with disabilities.

This selection may also be purchased at the cost of \$14.80 from: ABLENET; 360 Hoover Street, NE; Minneapolis, MN 55413. Tel. (612) 331-5958.

**Victims, Aggressors, and the Family Secret: An Exploration into Family Violence**, C. Watkins, Minnesota Department of Public Welfare, 1982. This book explores what is known about violence when it occurs in the family. Commonalities among family aggressors and victims are identified. Content includes: the sociology of family violence; definitions and statistics; family dynamics; health and family violence; the economics of family violence; and intervention strategies. In addition, guidelines are provided on resources needed for family violence intervention such as housing, volunteer services, and caregiving services.

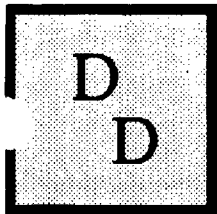
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## METROPOLITAN COUNCIL DD PROGRAM NEWS

### 1987 AGENDA: INTEGRATION AND QUALITY

Earlier issues of this publication discussed the phenomenal rapidity with which changes are occurring in the DD service system. The changes have come about because of what some parents have always maintained about the greater potential of their children who are severely handicapped and what leading professionals have demonstrated as higher outcomes for this population. Their research and demonstration of more effective service strategies are documented in what may be the most voluminous collection of data in the DD field to date.

ut having facts and data available is not always an adequate basis for changing our attitudes and expectations. Obstacles to changes include satisfaction with what is, need for stability and continuity in one's life, fear of the unknown, lack of adequate or accurate information about new ideas, and self-doubt about how to apply directives to very difficult and uncharted individual situations. Most people concerned about persons with developmental disabilities, therefore, cling to what they know, can see and touch. The DD service system in Minnesota has tended to develop with a heavy reliance on "specialized facilities" in the residential (ICFs-MR), habilitation (DACs), and rehabilitation (sheltered workshops) sectors. These facilities represent substance, continuity, protective standards, etc., to many parents and practitioners.

But advanced professional ideas and practice challenge our total dependency on facilities. The new perspective puts the emphasis of services on the outcomes they should produce in the quality of life for the persons receiving services. This view forces us to redefine services not as ICFs-MR, DACs, and sheltered workshops, but rather as the assistance and adaptations that individuals with developmental disabilities need to be able to live in an integrated society as self-sufficiently as possible. These services must also be consistent with the individual's strengths, preferences and interests. The

service setting is the total community, not a segregated or socially insulated building. Since we no longer consider "specialized facilities" as providing the stable, continuing, substantive foundation of services, what can we rely on? What can protect the advances that have been made? In a recent presentation in Minnesota, Dr. Lou Brown said that the most valid safeguards are the law and advocacy.

### Community Integration Project Seeks Sites

The Center on Human Policy, through its Research and Training Center on Community Integration and its Community Integration Project, is seeking sites for statewide or regional conferences on the state-of-the-art in community integration.

Staffed by national consultants and faculty and staff from the Center on Human Policy and Division of Special Education and Rehabilitation at Syracuse University, these conferences will be oriented to state officials, parents and consumers, professionals, and regional and local administrators. The conferences will be based on the work of the projects over the past three years. They will cover such topics as national exemplary practices in community living, parent involvement, administration and funding of community services, supports for people with challenging needs, family supports, and self-advocacy.

All conferences will be held between September and December 1987. Applications are due by June 15, 1987, and can be obtained by calling (315) 423-3851 or writing: Center on Human Policy; Syracuse University; 724 Comstock Avenue; Syracuse, NY 13244-4230.

### Call for Presentations

The Minnesota Division of Early Childhood fall conference will take place Oct. 15 in the Twin Cities Area. The division is requesting applications from Minnesotans who are interested in presenting a topic in the area of early childhood special education. Presentation time will be approximately one hour and 15 minutes. All proposals will be considered by the

conference program committee. No honorariums or other expenses can be reimbursed. To receive a presentation form or for other information write: Sandy Fink; 6010 159th Lane, NW, Ramsey, MN 55303; (612) 295-5185.

### **Employment Opportunities**

The Twin Cities Society for Children and Adults with Autism, Inc. is seeking qualified applicants for a program coordinator, a live-in (night) counselor, and full-time/part-time day and evening counselors for a supported living service for three young adults with autism. For information, contact: Renee Moen, (612) 228-9074.

### **Request for Volunteers**

■ A volunteer is needed to serve as a scoutmaster for a Boy Scout troop for teenage boys with mental retardation in West St. Paul. The volunteer needs to be 21 years of age or older and available to meet with the group every other Monday evening. Volunteers are also needed to assist with Special Olympics Track and Field practices and meets. If you can help, please call Mary Ellen at (612) 431-3700, at the Association for Retarded Citizens Suburban.

■ A Girl Scout troop of 18 girls at Humboldt High School is hoping to find adults willing to assist its troop this fall. This group is made up of girls with special needs who have high functional levels. Because they come from a variety of neighborhoods, transportation after school hours would be difficult. For this reason, the group is expecting to meet during school hours. The girls are 14 to 21 years old. "Girl Scouting is recreational, social and educational," explained Molly Pirjeveck, Girl Scouting coordinator for the Humboldt area. "The emphasis in the troop is on lifestyle and the activities reflect the interests of the girls, leaders and parents." Interested persons may also consider becoming leaders of other troops for girls age 5 to 21. If you are interested in helping the Humboldt group, another troop, or in starting your own troop, please call Molly at (612) 227-8835.

### **RESOURCES/SERVICES**

#### **■ Services for Eligible Children**

Services for Children with Handicaps, an agency of the Minnesota Department of Health, will cover the costs of diapers and/or incontinence pads for children over age four who are physically or mentally incapable of complete bladder or bowel control. The services also provides diagnostic evaluations and can pay for treatment of children with long-term physically handicapping conditions or chronic illnesses. The program also provides genetic counseling at no cost to the family. To learn more about requirements for this

coverage, contact district offices or the central office at (612) 623-5150.

#### **■ Special Phone Services Offered**

Northwestern Bell's Special Needs Center provides a variety of products and services for customers with disabilities. One example of interest to persons with mental retardation is a discount on the "speed calling 8" feature, which allows a person to use a single digit to reach frequently called numbers. Also, persons who can certify that they have a disability can borrow from \$50 to \$1,600 without interest to purchase special equipment. For information, call 1-800-223-3131, TDD/voice.

### **RECREATIONAL/LEISURE ACTIVITIES**

#### **TapeMark 10K-5K Run**

Calling all runners and walkers. Mark your calendars now for the 1987 TapeMark 5K and 10K runs to be held May 31. The 10K will start at 9 a.m. and the 5K will begin at 9:10 a.m. The entry fee is \$7. For more details, call ARC St. Paul, (612) 224-3301.

#### **YMCA Classes and Day Camp**

The St. Paul Skyway YMCA is again offering fitness classes for persons of all ages with mental and physical handicaps. It will also be offering a summer day camp for persons age 12 to 21 who are mentally retarded. It will be held Aug. 10-14 from 9 a.m. to 4 p.m. The Northwestern YMCA will have a summer day camp Aug. 17-21 from 9 a.m. to 4 p.m. Each day includes swimming lessons, gym time and trips to parks. A trip to the zoo and bowling is also offered. Cost for the week is \$52 and scholarships are available. For more information, or to register, call Lisa Anderson at (612) 292-4130.

#### **Wilderness Integrated Program Workshop**

A workshop titled *Wilderness Integrated Programming* will be presented cooperatively by Wilderness Inquiry II and the University of Minnesota's Integrated Therapeutic Recreation/Outdoor Education Project. If you are interested in the concepts and logistics of providing wilderness canoe adventures that include people with physical or cognitive disabilities, we think you will find this to be a stimulating and informative experience. Note that the workshop activities will be at two different sites on Wednesday, May 13, 1987. Cost: \$8 (includes lunch, or \$5 if you bring your own lunch). The two activities are as follows:

■ **8:30-Noon at Earle Brown Continuing Education Center, University of Minnesota, St. Paul Campus** - Session presents an overview of program outcomes from integrated wilderness trips, including: management

components of integrated programs, staff training issues, safety and liability, participant recruitment and screening, and program evaluation.

**Noon-3:30 at Roseville Central Park, Lake Bennett Landing.** - There will be a "Voyageur Lunch" (bring your own cup, bowl and spoon). Then learn about field techniques for integrated wilderness canoeing. Session will present adaptations and techniques that enable people with disabilities to participate on wilderness canoe trips.

Speakers will include staff members from Wilderness Inquiry II, the University of Minnesota's Division of Recreation, Park and Leisure Studies, and the YMCA. Equipment is provided by Wilderness Inquiry II. For further information: Wilderness Inquiry II; 1313 Fifth Street SE.; Suite 327A; Minneapolis, MN 55414; (612) 379-3858 (voice or TTY).

### **Free Workshop for Guides**

The City of Bloomington's Office of Special Services and Hennepin Parks are cosponsoring a FREE workshop to teach individuals to become guides for runners and/or tandem bikers who have visual impairments. This workshop will take place on Monday evening, June 1, 1987, from 7-9 p.m. at Hyland Hills Recreation Center, 10145 E. Bush Lake Road, Bloomington. Participants will learn and practice the techniques of guiding runners and tandem bikers. In order for individuals with visual impairments to enjoy these two healthy outdoor activities on an on-going basis, a runner's and/or tandem biker's volunteer guide list will be initiated at the workshop. If further information is needed, call the Office of Special Services at (612) 881-5811, Ext. 391 (TDD 887-9677) or to register, call the Hyland Recreation Center at 941-8724. The registration deadline is May 22, 1987. Everyone is welcome.

### **Summer Camping**

Registrations are currently being accepted for summer camping programs and vacations for children and adults with mental retardation or developmental delay. Offered by Eden Wood Camping and Retreat Center in Eden Prairie, selections include sports and health, creative arts and leisure specialties sessions, as well as trips to the boundary waters, state parks and lake cabins. Special weekends are also offered for families and for siblings of children with handicaps. Program fees range from \$220 to \$235 for most one-week sessions. Eden Wood is operated by the Association for Retarded Citizens (ARC) of Hennepin County. Program information and registration materials are available by calling (612) 874-6650.

### **Camp New Hope Ventures**

Persons of all ages with mental retardation and other

developmental disabilities are welcome at Camp New Hope in McGregor, Minnesota. With facilities that are accessible to individuals in wheelchairs, Camp New Hope serves people who might have limited options available to them. Regular features include swimming and boating, field trips, nature and art activities, visits to the pet farm and garden, and much more. Special sessions are scheduled for canoe trips and the Exceptional Theater.

Registrations are being taken for the 11 five- and six-day sessions planned for 1987. Camp New Hope is a nonprofit organization. Through the support of many service clubs and civic organizations, financial assistance is available for all who wish to attend. It is the philosophy of Camp New Hope that no one will be prohibited from attending due to financial need. For more information, contact Nancy and Bill Benson; Camp New Hope; H.C.R. 3 Box 578; McGregor, MN 55760; (218) 426-3560.

### **PUBLICATIONS**

**Staff Development in Mental Retardation Services: A Practical Handbook.** J.F. Gardner and Michael S. Chapman, Paul H. Brookes Publishing Co., 1985.

This publication was written as a basic guide for students who intend to work with persons who are mentally retarded. However, the contents are substantially applicable to persons who are developmentally disabled but not mentally retarded. The handbook is also an excellent tool for current service providers since the informational content expresses state-of-the-art principles or assumptions about this whole group of people. The text is punctuated with very concise statements reflecting these new theories.

Examples:

--"The person is more important than the diagnosis or label."

--"Community participation is increased by using generic rather than specialized services for people with mental retardation."

--"People with mental retardation have the same constitutional and statutory rights as other citizens."

The book is designed so that the reader can engage in interactive learning using exercises in each chapter. Each chapter has a quiz to help determine how much the reader currently knows about the chapter's subject matter. Then the learning objectives are stated, the topic is discussed and a concise summary is provided. Next, a case study is provided so the reader can immediately apply the new learning by answering a few questions raised in the study. Finally, case study answer guidelines are provided to help the reader determine whether the important issues were covered in the reader's responses.

Particularly useful for current practitioners are the

sections on the planning process using the team approach, writing behavioral objectives and translating those objectives into instructional strategies. These two steps are key tasks that most direct-service providers must master in dealing with the severely impaired learner. The book can be obtained by prepaying \$19.95 to Paul H. Brookes Publishing Co.; P.O. Box 10624; Baltimore, MD, 21285, or by calling toll-free (800) 638-3755.

**The Right to Grow Up: An Introduction to Adults with Developmental Disabilities;** Jean Ann Summers (Editor); Paul H. Brooks Publishing Company, 1986.

This book covers issues and services needed by persons with developmental disabilities in their adult years. It examines how the needs of people with developmental disabilities change as they move through the various stages of adulthood. It discusses what services are necessary (including a chapter on independent living programs) to provide the training and support needed by adults with developmental disabilities to participate successfully in their community, at home, at work, and in recreation and leisure activities.

The book explores policy and legal issues with chapters on self-advocacy, federal legislation, and administrative and policy trends. In light of state-of-the-art principles, the book says we know now that there are differences in cultural expectations for adults with developmental disabilities. Being an adult involves both freedom of choice and action, and responsibility for one's self and others. Thus the primary task of services for adults are to create options for informed choice and to assist them in developing the skills that allow them to assume as much responsibility for themselves and others as possible. This book provides an excellent introduction to the issues that parents and practitioners must address when dealing with adults who are developmentally disabled.

**The Right to Grow Up** can be ordered by prepaying \$21.95 to Brookes Publishing Co.; P.O. Box 10624; Baltimore, MD, 21285, or by calling toll free: (800) 638-3755. A copy is also available on loan from the State Developmental Disabilities Program (612) 296-4018.

**Children With Spina Bifida: Early Intervention and Preschool Programming.** G. Gordon Williamson (Editor); Paul H. Brookes Publishing Co., 1987.

The latest information on spina bifida, from the areas of medicine, therapy, and education is now available in a single volume. This well-illustrated resource brings the reader up to date with practices based on the most current research in the field and state-of-the-art techniques that the reader can apply every day whether the reader is a professional or a parent. The book contains sections on medical and health needs, positioning and mobility, learning and developmental

and daily living activities. It uses illustrations throughout to augment the text. Cost: \$23.95. The book may be ordered from the Spina Bifida Association of America: 1700 Rockville Pike; Suite 540; Rockville, MD, 20851-1800-621-3141.

## FEDERAL HIGHLIGHTS

### Civil Rights Restoration Act Introduced

After several attempts by Congress in recent years to amend federal acts weakened by three Supreme Court decisions, a new initiative has been launched. The Civil Rights Restoration Act seeks to forbid **agency-wide** discrimination on the basis of age, sex, race or handicapping condition. The court decisions ruled that discrimination was unlawful only in regard to a specific program or activity receiving federal money but not to the entire organization responsible for the program. The laws were originally too ambiguous and this latest bill is Congress' attempt to be more specific in its language.

The new bill will strengthen Title IX of the Higher Education Act (right to sue for appropriate, least restrictive education with recovery of costs for winner), Title VI of the Civil Rights Act, Section 504 of the Rehabilitation Act and the Older American's Act. On February 19, 1987, the legislation was introduced in the Senate. The prime sponsor was the new chairperson of the Labor and Human Resources Committee, along with 51 cosponsoring senators. Thus, S.557, the Civil Rights Restoration Act of 1987, coauthored by Sens. Edward Kennedy (D-MA) and Lowell Weicker (R-CT), has a much brighter future in the current senate than its predecessor bill in the 99th Congress. On February 24, 1987, in the House of Representatives, Rep. Augustus Hawkins (D-CA), together with Rep. Don Edwards (D-CA) reintroduced a companion bill, H.R. 1214, along with 110 cosponsors. Like the senate bill, it has significant bipartisan cosponsorship.

## SUMMER COURSES OFFERED AT ST. CLOUD STATE UNIVERSITY

A series of one-credit courses will be offered by the Department of Special Education at the St. Cloud State University in St. Cloud, Minnesota:

**July 6-7 Wellness I.** Presented by Quentin Robley.

**July 8-9 Wellness II.** Presented by Quentin Robley

**July 13-14 Community Integration.** Eva Gadberry, Ph.D., will present issues and strategies of effective integration of individuals with handicaps into community settings for living, working, and leisure.

**July 20-21 Legal Issues.** Larry Ringer and Eva Gadberry present current legal questions and answers in special education.

For more information and registration, contact: Eva Gadberry, Ph.D., Professor; Department of Special Education; College of Education; St. Cloud State University; St. Cloud, MN 56301. Tel. (612) 255-2041.

# INFORMATION EXCHANGE

STATE  
SUPPLEMENT

Developmental Disabilities Program

201 Capitol Square Building  
550 Cedar St.

St. Paul, Minnesota 55101

Minnesota State Planning Agency

Roger Strand, Editor

612/296-4018

Member of

National Association of  
Developmental Disabilities  
Councils

MAY 1987

## NEGOTIATED SETTLEMENT IN WELSCH CASE REACHED

On April 14, 1987, both parties in the **Welsch** Consent Decree, the Department of Human Services (DHS) and Legal Advocacy for Persons with Developmental Disabilities, signed a Negotiated Settlement. Both parties have agreed to file a joint request to the Federal Court to extend the expiration of the Consent Decree from June 30, 1987, to September 30, 1987. A Negotiated Settlement process will avoid further litigation over compliance by DHS and the regional treatment centers with the terms of the 1980 Consent Decree. The terms of the Negotiated Settlement are contingent upon two factors: (1) upon the final approval by the U.S. Federal District Court; and (2) upon the passage of amendments to the state's appeal statute which would allow appeals of case management decisions by county agencies.

Regarding the first contingency, a hearing on the Negotiated Settlement is scheduled at 9:30 a.m. on June 5, 1987, at the U.S. Federal District Court in Minneapolis, when statements from class members will be considered. People who wish to testify must file a written statement with the Clerk of the U.S. District Court in Minneapolis two days prior to this hearing.

Regarding the second contingency, if the legislation to amend the state's appeal statute regarding case management decisions is passed during the 1987 Regular Session of the Legislature, the remaining provisions of the Negotiated Settlement would become effective. The parties have agreed upon language amending the appeals statute and are prepared to jointly support the legislation.

The major items in the Proposed Negotiated Settlement include:

- DHS will agree to maintain staff ratios for the next two years in the regional treatment centers at the level contained in the 1980 Consent Decree.
- DHS will restrict the placement of children in regional treatment centers and require a variance of the facility's license when a child is placed in a regional treatment center.
- DHS will support legislation establishing an external monitoring system designed to investigate and evaluate services provided to persons with mental retardation in

regional treatment centers and community programs. The court monitor's office will continue for a period of time under the terms of the Negotiated Settlement with functions similar to an external monitoring office. If legislation establishing an external office is passed during the time period the Negotiated Settlement is in effect, the court monitor's office will end.

- DHS will prepare a number of reports, conduct a number of case reviews and field audits and provide certain specified data and documents to plaintiff's counsel during the time period the Negotiated Settlement is in effect.

- The Licensing Division of DHS will conduct on-site reviews of licensed community programs for which there are outstanding initial notices of non-compliance from the Court Monitor.

- DHS will issue a report by September 30, 1988, on the relationship of caseload size to case management services.

- By October 3, 1988, DHS will develop and revise the following two rules and submit them to the **State Register** for publication:

(a) Develop a licensing rule for individuals or agencies which provide certain services to persons with mental retardation under the state home and community-based waiver program; and

(b) Revise the Residential Services rule governing services to persons with mental retardation (Rule 34).

- DHS agrees to discharge 100 persons with very severe disabilities from regional treatment centers (or 25 percent of the total number of persons discharged during 1987-89 biennium, whichever is less).

The jurisdiction of the Federal Court will expire when DHS complies with the last four items listed above.

### Some People's Views

Several people were contacted and asked to respond to the following questions:

1. What do you think have been the most significant accomplishments as a result of the past 15 years of litigation in the **Welsch** case?

2. What are the greatest strengths or advantages in the current Negotiated Settlement?

3. In your opinion, what should have been included or considered in the Negotiated Settlement?

The people contacted and their responses to these questions are as follows:

**Julie Brunner, Director of Welsch Compliance, Department of Human Services:**

1. The Welsch case was helpful in focusing attention on the treatment and programming for persons with mental retardation in regional treatment centers.

2. The Negotiated Settlement permits the Department to use its resources to improve and strengthen the service system for community-based programs. It also removes some reporting requirements from regional treatment centers which permits resources in that system to go toward providing services to residents.

3. The Department is very satisfied with the Negotiated Settlement. Many items and issues were considered during our negotiations. Both parties had to compromise in order to reach a settlement. We believe this compromise results in a balanced agreement which is mutually beneficial to the parties.

**Luther Granquist, Attorney for Plaintiffs, Legal Advocacy for Persons with Developmental Disabilities of Minnesota:**

1. The most significant accomplishment has been an overwhelming reduction of children being admitted to state institutions.

2. We did not force the Department of Human Services to defend the indefensible--either in terms of institutional programs or the Department's failure to monitor the quality of community-based services. The settlement takes sound, first-steps in the establishment of quality assurance measures, such as field reviews by DHS personnel and the establishment of what should be an effective appeal process relating to the quality of individualized services.

3. I would have liked to have seen a sound plan for the reduction in case management caseloads and a commitment of substantial resources to provide effective training for county and provider personnel.

**Richard Cohen, Court Monitor for Welsch:**

1. The greatest accomplishment has been quantitative--the reduction in numbers of persons residing in state facilities. However, on the qualitative side, not enough has been accomplished; either in the regional treatment centers or in the community. Although there have been improvements, such as less use of major tranquilizers, mechanical restraints and use of aversive procedures, there is much further to go. Welsch has also (directly or indirectly) contributed toward getting the Home and Community-Based Waiver Program passed and also in creating equal incentive to

place people in the community as opposed to placement in the institution, although not all disincentives have been removed.

2. The greatest hope in the Settlement is that more persons with severe physical and behavioral handicaps will be placed in the community. There is further prohibition of placement of children in institutions and then only for a short time. It is envisioned that soon there will be no children placed in regional treatment centers. Another positive outcome can be the passage of legislation which will strengthen the appeal mechanism by adding a conciliation process and timeframes, which will enhance the quality of case management services.

3. There are system changes which need to be addressed, such as the need for comprehensive training of personnel in community and state programs. Such training is necessary because much of what is being done does not result in true skill development, integration, and more independent living for persons with severe handicaps. Furthermore, caseload sizes must be reduced in order to do effective case management. There should also be greater assurance that placement of persons with severe physical or behavioral handicaps in community programs can be accomplished without sacrifice to the quality of services provided. In addition, the Settlement does not address the funding and resource question--there are no means to permit money to flow with the client to allow for flexibility in living arrangements and acquisition of appropriate services.

I look forward to working with consumers, advocates, public and private providers, and personnel in government regarding the areas in the Settlement. Hopefully we will all have an impact on some of these broader and related issues.

**John Clawson, Executive Director, Minnesota Council for the Handicapped:**

1. Clearly there has been a heightened public awareness of people who are different. All people with disabilities have gained in this respect. There is greater sensitivity to the appropriateness of where people live--in and part of the community. There has been a significant shift to supporting people in the community.

2. The Settlement is going to be less expensive for the state and the plaintiffs. There will also be an end to a court monitored system.

3. The Settlement seems to end with a whimper instead of a bang. I don't see the more dramatic things that will significantly change the system, such as the continued depopulation of state facilities, the shifting of funding patterns to support families, and the prevention of institutionalization in the first place.

**Lyle Wray, Former Court Monitor and currently Director of the Dakota County Human Services Department:**

1. The Welsch Consent Decree has had an impact on

both institutional and community programs. On the institution side, it has protected people from substantial budget cuts. It has also highlighted alternatives to intensive treatment, particularly the need to reduce the use of psychotropic medications for persons with mental retardation. On the community side, the need for effective case management as the central point of maintaining a community service system has been recognized. Success stories have been highlighted in terms of persons with challenging behaviors and medical conditions. However, on the negative side, we have become more aware of the shortcomings in our service system, such as the need for new models in residential options, community integration, and work.

2. This is an honorable, credible settlement. It assures that regional treatment centers will maintain basic levels of staff to provide services and it emphasizes the need for special services, such as physical therapy. There is also a continuing emphasis on the needs of people with challenging behavior and the need to serve this population better in the community. The importance of improving case management services is addressed.

3. What remains to be done is the need to work on funding reform, with Medical Assistance at the federal level to support family living and work arrangements. Dollars should follow clients more easily from the institution to the community. We must strengthen and demonstrate the effectiveness of case management. We must strengthen and support innovations, such as personnel training so that staff can try out new ideas, and new models of work and living arrangements. Finally we need to strengthen our whole approach to quality assurance with focus on outcomes, or results for clients.

**Duane Shimpach, Director, Faribault-Martin-Watonwan Human Service Board:**

1. Welsch raised our level of expectations and gave the system a focus among all parties involved. It also mobilized resources to improve quality of living standards for clients.

2. I really prefer to wait and see what benefits there may be for clients. Personally, I don't see any. It probably means good business for consultants, attorneys, and monitors. There really seem to be too many vague definitions, assumptions, and implied activities.

3. I would have liked to see more consideration given to those still stranded in the regional treatment centers. There should have been representation from community service providers and from the counties in the discussion of the Negotiated Settlement. There are system changes needed to enable the successful attainment of our mission after termination of court jurisdiction. Finally, there is a need to state the performance outcomes, definitions, reasonableness, and need within the Negotiated Settlement document itself.

**Ralph McQuarter, President, Minnesota Association for Persons with Severe Handicaps:**

1. Personnel in regional treatment centers have been held more accountable. Welsch has also provided momentum for the development of community programs. There has been an impressive movement of about 1,000 people (including children) out of institutions to community programs. Welsch has also given advocates credibility, strength, and confidence that things can be changed.

2. The proposed Settlement would provide for outside monitoring, independent of the provider, or another department. This monitoring would be based on New York's Quality of Care Commission, unlike Minnesota where we both license and administer state-run programs by the same department. It moves more people into less restrictive settings including the people considered the most challenging. It keeps children out of the state institutions unless a waiver is obtained.

3. I have two concerns: One is that more people should be moved out (of regional treatment centers) because we have demonstrated that people with severe handicaps can participate in the community. The other concern is that there is not an adequate provision for staff training for county and other providers of services.

There is a great need for competency-based and value-based training in all sectors. Furthermore, I feel that we should consider using other vehicles for change; we can't expect the Settlement to be an answer to everything.

**Beverly Driscoll, Associate Director, Minnesota Association of Counties:**

1. A significant accomplishment has been an intangible but pervasive and enduring benefit--an awareness of the possibilities for persons with mental retardation or related conditions. The most dramatic change is probably the alteration of lifestyle in living arrangements, day activities, and work experiences.

2. A significant advantage of the Settlement is that the responsibility for operating the program for persons with mental retardation is returned to the state agency while establishing an external monitoring system. It is important to protect diversity in services for persons with mental retardation, a diversity that may not always provide optimum services but one which provides good services for the individual.

3. No comment at this time.

**Betty Hubbard, President, Association for Retarded Citizens of Minnesota:**

1. (a) Change in society's perception of persons with mental retardation as hopeless dependents to citizens with potential for growth and self direction. (b) Improved staff/resident ratios in the regional treatment centers, and decreased use of psychotropic medications. (c) Requiring individualized service plans which recognize and build on individual strengths and needs.



(d) Encouraging the development of community alternatives to institutional placement.

2. (a) The proposed administrative review of case management decisions. (b) Prohibition against the placement of children in regional treatment centers. (c) Requirement to move regional center residents with severe and multiple disabilities into appropriate community settings.

3. (a) Establishment of an external quality assurance monitoring system. (b) Mandated training for case managers, day and residential programs staffs, etc. (c) Mandated case management ratios. (d) Some required extrapolation to community - example: monitoring of use of psychotropic medications and aversive and deprivation procedures in community day and residential settings as well as regional treatment centers.

Copies of the Negotiated Settlement may be requested from either of the two following sources: (1) Legal Advocacy for Persons with Developmental Disabilities of Minnesota; Legal Aid Society of Minneapolis; 222 Grain Exchange Bldg.; 323 Fourth Av., S.; Minneapolis, MN. 55415; or (2) **Welsch** Compliance Office; Department of Human Services; Fourth Floor, Centennial Office Bldg.; 658 Cedar Street; St. Paul, MN. 55155.

#### **DEVELOPMENTAL DISABILITIES PROGRAM AT GILLETTE CHILDREN'S HOSPITAL TO BE TERMINATED**

On April 24, 1987, the staff members of the Developmental Disabilities Program at the Gillette Children's Hospital were informed by Margaret Perryman, Administrator, that patient evaluations would be discontinued by the end of May 1987. At that time, the program will end.

The Developmental Disabilities Program has provided exemplary services to young people with difficult, rare, and unusual disabilities. These patients require extensive professional services. Third party payers such as insurance companies, health maintenance organizations, and government agencies cover only part of the cost. As a result, the Developmental Disabilities Program has been unable to meet its expenses and has depended on other hospital revenues to operate. Because the hospital can no longer support the Developmental Disabilities Program, the program must be discontinued.

Layoffs will affect ten medical and ancillary employees (7 full-time equivalents). Some of these employees will retain their part-time positions or fill vacant positions in other departments. Only staff members in the Developmental Disabilities Program are affected.

According to Perryman, a committee will be appointed to address the needs of patients and their families.

"We regret the loss of the Developmental Disabilities Program," said Perryman, "however, it is necessary for us to achieve financial stability, adapt to the health care marketplace, and preserve our mission. As we become

financially stable, we hope to strengthen our programs in orthopedics, head injury, epilepsy, rehabilitation, orthotics, and prosthetics."

Questions should be directed to: Margaret Perryman, Administrator, Gillette Children's Hospital; 200 East University Avenue; St. Paul, MN 55101. Tel. (612) 291-2848.

#### **HARRIS STUDIES EMPLOYER ATTITUDES AND PRACTICES**

Although an overwhelming majority of employers rated the performance of workers with disabilities as good to excellent in a recent national Harris survey, over half of the employers surveyed cited the lack of qualified applicants as the most important reason that people with disabilities were not hired. *Employing Disabled Americans* is a report soon to be released by Louis Harris and Associates who studied employer attitudes and practices regarding workers with disabilities. The study was commissioned by the President's Committee on Employment of the Handicapped, the National Council on the Handicapped, and the International Center for the Disabled.

The purpose of the study was to learn what employers across the nation are doing to employ people with disabilities and what their experiences have been. The survey also attempted to identify the barriers that prevent employers from hiring people with disabilities, and steps that the public and private sectors could take to increase the employment of people with disabilities. In all, 921 telephone interviews were conducted with managers of 921 companies of various sizes throughout the country during September and October of 1986.

The study revealed that nearly all employees with disabilities do their jobs as well or better than other employees in similar jobs. The great majority of managers say that disabled employees work as hard or harder than nondisabled employees and are as reliable and punctual or more so. They produce as well or better than nondisabled employees and demonstrate average or better-than-average leadership ability. They are also ambitious. In other words, employees with disabilities are generally an asset to any employer.

Aside from job performance ratings, there were these findings:

- Of the companies with at least 10,000 employees, 52 percent have hired people with disabilities in the last year, but that figure drops to 27 percent for companies with 50 to 999 employees and 16 percent for companies with 10 to 49 workers.

- Fifty-seven percent of equal opportunity officers said that their company had not hired a person with a disability in the last year, and thirty-five percent of them said their company had not hired a person with a disability in the last three years.



- Sixty-seven percent of top managers, seventy-one percent of the equal employment officers, and seventy percent of department heads thought that their companies are doing enough now to employ people with disabilities.

- Eighty-one percent of top managers, seventy percent of the equal employment officers, and seventy-five percent of department heads said it costs about the same to employ a person with a disability as a person who is not.

- Of the top managers, 75 percent felt that persons with disabilities often encounter discrimination from employers.

- Only 37 percent of the companies had policies or programs for hiring workers with disabilities.

- The majority of managers report that their companies can provide in-house training for employees with disabilities.

Harold Russell, Chairman of the President's Committee on Employment of the Handicapped, presented these preliminary disclosures of the study at a news conference held at the Hyatt Regency Hotel in Miami on February 4, 1987. Russell cited the study's significant directions for business and government leaders to tackle the immense unemployment problems among people with disabilities. He also listed some of the findings that could be turned into social and economic policy actions: (1) increase the pool of qualified persons with disabilities through education and increased training efforts; (2) design a model policy for all companies to adopt and adapt on the hiring of employees with disabilities; (3) enlist the support of top management in raising the consciousness of middle managers about employees with disabilities; and (4) eliminate job discrimination against people with disabilities. He concluded by emphasizing that the study finds enormous goodwill among employers. It's up to us to turn this goodwill into action.

Copies of the report may be requested from: National Council on the Handicapped; 800 Independence Avenue, SW, Suite 814; Washington, DC 20591. Tel. (202) 267-3235.

## CONFERENCES/WORKSHOPS

### May 7, 1987

**National Barrier Awareness Day** will be observed from 11:30 a.m. to 12:30 p.m. at a rally at the State Capitol Rotunda in St. Paul. The event will highlight the progress of Access 92 as initiated by the Minnesota State Council for the Handicapped. Join the commitment to a barrier-free Minnesota by 1992.

### May 16-18, 1987

**National Conference on Independent Living** will be held at the Ramada Renaissance Hotel, Washington, DC. Contact: Susan Elkins, Program Coordinator; Independent Living Conference; AA 313 Bristol Terrace; Lawrence, KS 66044.

### May 26-29, 1987

**Two Decades of Excellence: A Foundation for the Future** is the theme of the **Biennial Conference of the American Deafness and Rehabilitation Association**, which will be held at the Sheraton Park Place Hotel, Minneapolis. Contact: Deb Guthmann; University of Minnesota; 101 Pleasant Street, SE; 12 Johnston Hall; Minneapolis, MN 55455.

### May 27-29, 1987

**A Generation Worth Saving** is the theme of the **1987 Child Welfare League of America Mid-West Regional Conference** which will be held at the Westin Hotel in Detroit, Michigan. Contact: Betty Durfee; C.W.L.A. Registration Chair; North End Station; P.O. Box 02009; Detroit, MI 48202.

### May 28-29, 1987

**Supported Employment Strategies** is a workshop sponsored by Government Training Service/Minnesota Supported Employment Project that will be held at the Alexandria Holiday Inn on I-94 in Alexandria, Minnesota. Fee: \$75.00. For registration and more information, contact: Government Training Service; 202 Minnesota Building; 46 East Fourth Street; St. Paul, MN 55101. Tel. (612) 222-7409, or (800) 652-9719 toll free.

### June 20, 1987

**A Conference on Consumer Owned Housing Options** will be held at the Earle Brown Continuing Education Center on the St. Paul Campus of the University of Minnesota. Bob Laux of Creative Management Associates in New Hampshire will be the featured speaker. The conference is being planned by the Minnesota Department of Human Services, the Association for Retarded Citizens of St. Paul, and the Association for Retarded Citizens of Minnesota. Fee: \$25.00. For more information: Jane Wells; Creative Community Options; 4209 Oakmede Lane; White Bear Lake, MN 55110. Tel. (612) 426-9263.

## **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.**

**Cognitive Counseling and Persons with Special Needs: Adapting Behavioral Approaches to the Social Context**, Herbert Lovett, Praeger Publishers, 1985. This book describes the effective and humane use of behavioral methods to teach social and cognitive skills to persons with severe and profound levels of mental retardation. It serves as an introduction and guidebook that outlines general principles and case studies to illustrate the concepts under discussion. This book offers readers sound professional advice as well as emotional support and inspiration. For example, Lovett observed: . . . our perceptions and assessments of a person's abilities can become self-fulfilling prophecies. When we assume that individuals can learn to do anything, regardless of the label or presumed disability, then we are leaving it up to them to tell us their limits. For years we have defined the ceiling of capability for an entire population of our fellow citizens by saying, "They will be able to do this much and no more." And when we do not give them the opportunity to do more, the prophecy always comes true. Only when the lives of all allow the maximum opportunity for development will we know what an individual can really do (p. 23).

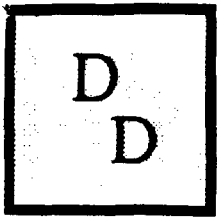
**A Guidebook for Parents of Children with Emotional Disorders**, Pacer Center, Inc., Minneapolis, 1984. This booklet was prepared by the Parent Advocacy Coalition for Education Rights Center (PACER) in response to the needs expressed by many parents in Minnesota: (1) to better understand the topic of mental illness; (2) the types of mental health treatment programs that serve children and youth; and (3) to have available the kind of information they need to make informed decisions. The contents is intended to provide readers with some guideposts to help them through the fog. The information is arranged in a question and answer format. A list of suggested resources and services available in Minnesota are provided as well as suggestions for further reading. The authors stress that, Knowing the right questions to ask and some starting places to look can help you find some answers for your child or young friend. Copies may be purchased for \$6.00 from PACER Center, 4826 Chicago Avenue, South, Minneapolis, MN 55417 (Tel. 612/827-2966), or may be borrowed from this lending library, as indicated at the top of the page.

**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,  
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# INFORMATION EXCHANGE



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## METROPOLITAN COUNCIL DD PROGRAM NEWS

### 1987 AGENDA: INTEGRATION AND QUALITY

Every now and then something is written which expresses so eloquently what one wishes one could say as well. Following are excerpts from **Community News**, a newsletter of Community Services for Autistic Adults and Children, Inc. of Rockville, Maryland. The article examines some of the forces which compel parents and professionals to dedicate their lives to the common goal of creating a good life for their sons, daughters, students and clients who have autism and other disabilities. It attempts to explain their fierce commitment to "community integration," "normalization" and "non-aversive behavior technology." And it looks at the "common ties between this commitment and the bedrock values which enabled the wider population--the people of this country--to create greatness in the wilderness which was (and in another sense is now) America."

"What is it that causes both parents and professionals to adopt ideologies and methodologies which dictate non-restrictive, integrated service and humane treatment?

"We know that many enter the field because they have a personal contact--either through their immediate family or through experience with a person who has a handicapping condition. And we assert that many pursue this field because of that thread of Judeo-Christian ethics which runs through our society, causing many to espouse humanism and altruism.

"And what about that rage, that sense of moral indignation, which many feel because they understand the unfairness of those perceptions, held by much of society, that people with severe disabilities are less than human, that they have not achieved equal status with people who are not disabled, and thus may be relegated to segregated, sterile environments or be

subjected to aversive experimentation?

"Perhaps there has occurred, in many of us, a 'catharsis of knowledge and conviction,' to use the words of Thomas Wolfe; a coming together, purifying and melding of what we know through empirical study and what we feel through our own empathy with severely handicapped human beings--love and care for them as our children, students and clients; sympathy for them and a sense of oneness with them as fellow human beings.

"Having adopted this attitude, it is easy to develop a sense of outrage toward devaluing policies such as institutionalization, exclusion from the community, compulsory sterilization, withholding treatment for people with treatable medical conditions, segregation in and exclusion from education.

"For many, the question arises: 'Why are we doing this? Why are we here?' It is often not as important to answer the question 'why are we here?' as it is to address the question 'what do we do now that we are here?' How do we keep our mission in perspective? If we profess to be in the business of helping persons with severe disabilities, or to follow a profession that compels us to provide assistance, support, advocacy, etc. for people with severe disabilities, it is only logical to adopt and promote those methodologies and ideologies that give these people the opportunity to be positively valued by society.

"We search for something better, a new society, the realization of a dream, a structure of life where children may grow up safe, where their different ways can be tolerated, and in which their lives can unfold and be valued unfettered by the restrictions of old and unjust configurations of power."

### PACER COMPUTER RESOURCE CENTER

The PACER Center has been selected as one of ten

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.

national sites by Apple Computer, Inc. to serve as a computer resource center for children and youth with handicaps and their families. In becoming one of the charter members of Apple's National Special Education Alliance, PACER will receive computer hardware with adaptive devices as well as programs written for use by young people with various handicapping conditions. Families will be able to come to PACER's office for demonstrations of differing computer applications. Potential users will be able to gain "hands on" experience with various types of equipment and software. The center is expected to begin its operations this summer. For more information: PACER Center; 4826 Chicago Avenue S.; Minneapolis, MN 55417-1055; (612) 827- 2966 (V and TDD).

## **AAMD SEEKS INTERNSHIP SITES**

Dr. Michael Maus, state chapter president of the American Association on Mental Deficiency (AAMD), is in the process of developing an internship program, which would connect students preparing for a career in mental retardation or related disciplines with organizations specializing in services to people who are mentally retarded. The Minnesota State Chapter of AAMD has committed resources to developing this program and is seeking sites and contacts for potential internship opportunities. If your agency would be willing to sponsor or cosponsor an intern for a special project, or has a unique learning opportunity in which a student would find educational value, please contact Mike and join us in developing the skills and education of our future colleagues. For more information: Michael Maus, Ph.D.; 900 4th Street SW; Austin, MN 55912; (507) 433-7301.

## **EMPLOYMENT OPPORTUNITIES**

### **Summer Staff Needed**

■ Camp Friendship has openings for counselors, recreation program leaders, nature leader, lifeguards, and nurses (RN and graduate nurses). Staff members are given an orientation to camp prior to working directly with participants. For more information, contact Georgann Rumsey at Camp Friendship; Route 3, Box 162; Annandale, MN 55302; (612) 274-8376.

■ Courage Center Camping Department is now recruiting and hiring summer staff for Camp Courage and Courage North for June-September 1987. Courage Center is seeking food service workers, cabin counselors and speech clinicians. Skilled nurses are also needed. Compensation includes housing and meals. Those interested in a rewarding summer job working with children and adults with disabilities should write or call the Courage Center Camping Department; 3915 Golden Valley Road; Golden Valley, MN 55422; (612) 588-0811.

**Focus Homes Inc.** is seeking qualified applicants for P.T.

program staff to work with adults who are deaf, deaf/blind and mentally retarded (ages 22-42). Duties: education and support in daily living skills, ASL communication, and social/recreational activities. Contact: Tia Smith, (612) 425-1604 (V/TDD).

## **REQUESTS FOR ASSISTANCE**

■ Focus Homes Inc. needs volunteers to be a "Big Brother or Big Sister" to one or more individuals who are mentally retarded, deaf or deaf and blind. For more information call Margie Cruz, (612) 425-1604 (V/TDD).

■ Camp Friendship would appreciate donations of equipment: 10/20 HP boat motors, a new or used paddleboat, an electric typewriter, file cabinets, inner tubes and three-wheel bikes.

■ Art Consultants are needed who have experience in the arts and desire to bring the arts into the lives of persons who are disabled. We want to expand our roster of artists statewide who may serve as workshop leaders for a day or extended lengths of time. If you are interested in serving as an arts consultant for Very Special Arts-Minnesota, please call Susan Harden at (612) 922-2928.

■ United Handicapped Federation  
Readers are asked to call or send information about:

- locations of **inaccessible** public places (whether labelled "accessible" or not),

- Metro Area contractors who can do construction retrofitting that meets state/local codes or addresses of places that are particularly well done.

UHF offers an old teletype mimeograph machine and an Adler electric typewriter to your organization. For information: Jackie Alfonso; United Handicapped Federation; 1821 University Avenue, #284S; St. Paul, MN 55104; (612) 645-8922 (V/TTY).

■ Spina Bifida Association  
The association would like donations or loans of the following equipment that have been requested with increasing frequency: thistle trikes, caster carts, walkers and standing frames. If readers have such equipment or can help search for it, please inform: Deb Hughes; 10201 Olive Street NW; Coon Rapids, MN 55433; (612) 757-7758.

■ Value Village Thrift Store  
Volunteer positions are currently available at Value Village Thrift Store in Richfield, whose proceeds benefit the Association for Retarded Citizens (ARC) of Hennepin County. Assistance is needed sorting and arranging merchandise, and in receiving donations from the community. Books, clothing, women's accessories, children's merchandise and furnishings are some examples of areas needing assistance. Both individua.

and civic groups are invited to participate. Hours are available weekdays, evenings and weekends. Please call (612) 866-3633 for further information.

## RESOURCES/SERVICES

### VSA-MN IS...

Very Special Arts Minnesota is a statewide nonprofit organization whose mission is to establish, improve and expand arts programs by, for and with children, youth and adults who are disabled and nondisabled. Through Very Special Arts Festivals, special projects and other programs, VSA-MN strives to bring individuals with disabilities a special new hope by creating and promoting year-round opportunities in drama, music, dance and the visual and media arts. Last year, across the state, more than 4,000 people participated in the VSA-MN Festival activities and several other projects, including dance and/or creative movement, signing to music, special education and art teacher in-service workshops, and children's "hands on" art demonstrations. The Special Network Project, funded in part by the National Endowment for the Arts, will expand Very Special Arts-Minnesota's activities by initiating a statewide advocacy, resource, and service network through a quarterly newsletter, **Promising Practices**. The artists, educators, administrators, students, parents, and the public who receive this publication can be stimulated to participate in and learn about arts education for individuals with special needs. For more information: VSA-MN; 5701 Normandale Road; Minneapolis, MN 55424; (612) 922-2928.

### Community Resource Booklet

Jim Mitchell of Opportunity SILS-SLS has developed a Hennepin County Community Resource booklet. It is 25 pages long, color- and picture-coded, and three-hole punched. Categories include: theatres, clubs and organizations, classes, transportation, places to visit, sports and recreation, plus information on library locations, housing and newspapers. It is being distributed by the Community Health Education Network (C.H.E.N.) for \$3.00. C.H.E.N. will include a one-page instructional sheet, "Teaching Telephone Use," free of charge. To order, send checks to C.H.E.N.; 3225 Lyndale Avenue S.; Minneapolis, MN 55408-3699; (612) 827-5641 or 1-800-582-5256.

## FOR YOUR INFORMATION

### ■ 1987 Phillips Awards

Nominations are now being accepted for the 24th annual Rose and Jay Phillips Awards. Each year, five individuals with physical disabilities are recognized for achieving vocational success despite their disabilities. Phillips Award recipients receive commemorative plaques and \$500 honorariums at a public ceremony to be

announced in the near future. The Phillips Award was created in 1964 to stimulate interest in and encourage the employment of people with disabilities by recognizing those who have achieved vocational success. Courage Center sponsors the awards, which are made possible by a gift from Rose and Jay Phillips of Minneapolis. Deadline for nominations is July 15, 1987. For information or nomination forms, contact Courage Center; 3915 Golden Valley Road; Golden Valley, MN 55422; (612) 588-0811.

### ■ Voter's Accessibility Manual

A guide to expanding accessibility to voting for persons who are disabled is still available free of charge. The manual, "Disabled Citizens at the Polls: A Guide for Election Officials," may be requested by writing to the National Organization on Disability; 2100 Pennsylvania Avenue NW, Suite 232; Washington, D.C. 20037.

### ■ Supporting Volunteer Evaluators

"Partnership for Quality Services" is a new brochure describing Association for Retarded Citizens (ARC) Minnesota's new project to train and support volunteer monitors to evaluate services for persons with developmental disabilities. The project is funded through joint support from the Minnesota Governor's Planning Council on Developmental Disabilities and ARC Minnesota. For a copy of the brochure, more information or to volunteer: Jean Swanson; ARC Minnesota; 3225 Lyndale Avenue South; Minneapolis, MN 55408; (612) 827-5641 or 1-800-582-5256.

### ■ Respite Care Brochure: Washington County

The Family Service of St. Croix Area has produced a brochure on respite care. It describes a volunteer caregiver service available to residents of Washington County who are disabled or chronically ill. The program is a model that could be replicated in other counties or localities. For a brochure and more information: Family Service of St. Croix Area; 216 West Myrtle Street; Stillwater, MN 55082; (612) 439-4840.

### ■ Social Skills Information

**News Digest**, is a free publication of the National Information Center for Handicapped Children and Youth. It devotes its most recent issue (No. 6) to practical suggestions for changing behavior, expressions that are socially valued, and promotion of increased social interaction. This issue also provides a lengthy list of further references. For a free copy of No. 6, or to request your addition to the mailing list, write: NICHCY; Box 1492; Washington, D.C. 20013. The Center also invites responses from readers about progress and successes that are occurring in local service areas. Send this information to a different address: NICHCY; 1555 North Wilson Blvd., Suite 700; Rosslyn, Virginia 22209.

## ■ Masters' and Doctoral Assistantships Available

Variety of positions for graduate students are available in the Division of Special Education and Rehabilitation Services, Syracuse University, Syracuse, NY. Positions carry tuition and stipends (\$6,000 and up). Program includes concentrations in: supported employment, transition, school and community integration, instructional technology and curriculum development. For more information call or write to Jan Nisbet, Division of Special Education and Rehabilitation, 805 S. Crouse Ave., Syracuse, NY 13244. (315) 423-4121.

## ■ Changes at Gillette Children's Hospital

The Developmental Disabilities Program at Gillette Children's Hospital discontinued services May 29.

Gillette will continue to provide evaluation and clinical services for young people who have difficult and multiple disabilities through other appropriate programs. Staff physicians, psychologists, therapists, and social workers will diagnose and make treatment recommendations for children who are physically disabled.

The Developmental Disabilities Program, organized in 1983, established a model for evaluation services. Because the costs of those services were only partially covered by third-party payers, the hospital could no longer support the program.

For information about optional evaluation services, contact Flossie Rafferty, admitting coordinator, at (612) 291-2848, extension 250.

## RECREATION/LEISURE ACTIVITIES

### Horseback Riding

**We Can Ride, Inc.** is a nonprofit organization that provides horseback riding for persons with handicaps. The program operates on the grounds of the Hennepin County Home School and uses their horses. **We Can Ride** trains some of the young people from the Home School and they serve as horse handlers for the riding classes.

The riders are children and adults who are handicapped. They are grouped by ability level. The type of riding class they are involved in will vary in length and scope. Some people come to learn riding skills. Some people receive actual physical therapy on the horse and others come for both. The class sizes vary. Some classes have physical therapists in attendance as well as the instructor. Each rider has a side walker on each side of the horse and a horse handler to lead the horse. Every effort is made to assure that each rider has good therapeutic exercise and a lot of fun.

Sessions are scheduled for: July 21/22 to August 25/26

and September 8/9 to October 13/14. For more information, contact We Can Ride, Inc., P.O. Box 1102, Minnetonka, Minnesota 55345. The volunteer coordinator is Kathy Magdal, phone (612) 933-5964.

## Courage Center Day Camp

The Courage Center Day Camp is a two-week program for children ages 7 to 14 who have physical disabilities. It emphasizes arts and crafts, nature study, outdoor skills and activities, socialization skills and fun.

For working parents, children may be dropped off at Courage Center at 7:30 a.m. Children will be supervised by a counselor and then leave for Islands of Peace Park at 8:30 a.m. Breakfasts can be purchased at Courage Center. Upon returning to Courage Center at 3:30 p.m., quiet activities will be available for children.

Time: day camp 9 a.m. to 3 p.m. Early morning and late afternoon arrangements 7:30 a.m. to 5 p.m. Days: Monday through Friday. Dates: July 27 to August 7. Location: Islands of Peace Park, Fridley, MN. Fee: \$55. Breakfast tickets: \$14. Lunch: please pack a lunch for your child. Juice or milk will be provided. Registration: deadline is Friday, July 17. The number of children is limited to 22 for the day camp and 10 for the early morning and late afternoon program. Applications are accepted on a first come, first served basis.

For a registration form or more information, contact Karyl Hoeger at Courage Center, (612) 588-0811, extension 199.

## CONFERENCES/WORKSHOPS

### June 20, 1987

*Consumer-Owned Housing Options.* Conference is sponsored by the Minnesota Department of Human Services, in cooperation with the Association for Retarded Citizens St. Paul, the Association for Retarded Citizens Minnesota and Creative Community Options. Featured speaker is Bob Laux of Creative Management Associates in New Hampshire. The conference will be held at the Earle Brown Center, St. Paul campus of the University of Minnesota. For registration information: Jane Wells; Creative Community Options; 4209 Oakmede Lane; White Bear Lake, MN 55110; (612) 426-9263.

### June 22-23, 1987

*Diagnosis and Treatment of Mental Illness in Persons with Mental Retardation.* This seminar is sponsored by the Minnesota Developmental Disabilities Achievement Center Association and features Frank Menolascino, M.D. and John McGee, Ph.D. as faculty. The seminar will be held at the Hotel Sofitel, Bloomington, Minnesota near Interstate Hwy. 494 and Hwy. 100. Registration and lunch on June 23 will cost \$105 per person. Reduced fees will be given to groups. Direct

inquiries by June 12, 1987 to: MNDACA; 1821 University Avenue, Suite 277; St. Paul, MN 55104; (612) 647-9200.

#### **August 31, 1987**

*Beyond Community Services toward Full Community Participation.* The Minnesota Chapter of American Association on Mental Deficiency will sponsor this workshop at the Radisson South Hotel. For more information: Mary Ann Stevenson, (612) 754-2505.

#### **September 1-2, 1987**

*Back to the Future: An Interagency Odyssey.* Sponsored by 12 Minnesota organization and agencies, the event will be held at the Radisson South Hotel; 2800 Normandale Boulevard; Bloomington, MN. The conference will highlight exemplary cooperative efforts presented by professionals, parents and agencies providing services to persons with disabilities and special needs. Several well-known speakers will augment this theme: Allen Crocker, M.D., Harvard Medical School; Tony Bouza, Chief of Police, Minneapolis Police Department; William E. Hudson, Brass Tacks Network; and Wy Spano and D.J. Leary, local political analysts. A number of separate pre-conference (August 31) workshops are being offered. Registration fee plus lunches is \$55 before August 14. For registration form or more information: Minnesota Organizations Registration; 1555 118th Ave. NW; Coon Rapids, MN 55433.

#### **September 14-16, 1987**

*Future Images for People with Severe Disabilities: Entitlement, Excellence, Empowerment* will be sponsored by New Concepts in Madison, Wisconsin. This is the second annual national forum for those committed to full community integration. The forum was attended by more than 300 people its first year and featured many nationally known speakers and a wide array of service specialties. Registration is \$95. Conference room rates for Inn on the Park: \$58 (single), \$66 (double). For registration brochure: New Concepts; P.O. Box 376, Middleton, WI 53562.

#### **FIRST NATIONAL FRAGILE X CONFERENCE ANNOUNCED**

The Fragile X Foundation has announced plans to host a national conference in Denver, Colorado, concerning the Fragile X Syndrome on December 3-4, 1987. Abstracts are also requested from professionals to present research or clinical experience in a poster presentation at this meeting.

Fragile X is a newly recognized disorder which results from a weakness in the structure of the X sex chromosome. Virtually unknown to doctors five years ago, Fragile X has come to be recognized as a leading cause of mental retardation among newborns in the United States, second only to Down Syndrome.

Conference registration forms or abstract information is available by writing: The Fragile X Foundation National Conference; c/o Expectations Unlimited, Inc.; 6897 Paiute Avenue, #2; Longmont, Colorado 80501. Tel. (303) 861-6630.

#### **PUBLICATIONS**

**A Comprehensive Guide to the Activities Catalog: An Alternative Curriculum for Youth and Adults with Severe Disabilities and The Activities Catalog.** Barbara Wilcox and G. Thomas Bellamy, editors; Paul H. Brookes Publishing Company; \$29.95. Persons with severe handicapping conditions do not live by services alone! They have other dimensions to their lives and this catalog and its accompanying guide address those other human areas. Rather than using the traditional academic approach to development, it selectively targets activities typically valued by everyone--disabled or not. The categories cover leisure, personal management and work activities. And within each category are many sub-categories, each describing from six to 25 different things to do and how to do them.

The guide provides well-written expositions about the rationale for the approach and how to use the catalog in school, residential, and employment settings or for evaluating programs. John O'Brien's chapter is particularly timely in its discussion of how to integrate natural support systems with more structured services. The catalog itself is practical, attractively illustrated and uses a very easy-to-follow format. In fact, it is a downright exciting resource. No person should spend another day, evening and weekend doing what someone else selects as an activity when this neat catalog portrays so many, many activities that can be selected by an individual by pointing a finger at a picture of that activity. The book may be ordered for a 30-day examination period by calling 1-800-638-3776 and charging it to an accepted credit card. Or mail your check to Paul H. Brookes Publishing Company, P.O. Box 10624, Baltimore, MD 21285-0624.

**Transition from School to Work: New Challenges for Youth with Severe Disabilities;** P. Wehman, M. Sherril Moon, J. M. Everson, W. Wood, & J. M. Barcus; Paul H. Brookes Publishing Co.; 1987. Beginning with a clear definition and rationale for transition services, the authors take the reader through the important stages that guarantee successful transition from the public school system to adult services: Step 1, prepare for transition in the school years; Step 2, initiate careful transition program planning; and Step 3, discover employment options and achieve successful placements. A copy can be ordered on a 30-day approval by calling Paul H. Brookes Publishing Company, toll free: 1-800-638-3775.

**The Industrial Work Model: A Guide for Developing Transitional & Supported Employment.** Barrett, J., & Lavin, D. University of Wisconsin-Stout, 1987. Based on

experiences gained at Rise, Inc., in Minneapolis, this publication serves as an introduction to the principles and methods used to develop and operate successful industry-integrated programs. It is intended to serve as a guide both for existing service providers who are interested in retooling their program model in the direction of industrial work services and other organizations who may be planning these programs for the first time. Chapters include: defining the program, setting up the program, marketing, administrative issues, staffing, and service delivery strategies. Cost: \$19.50. Available from: Rise, Inc.; 8406 Sunset Road, NE; Spring Lake Park, MN 55432. Tel. (612) 786-8334.

**A Resource Manual on Child Abuse: PACER's Let's Prevent Abuse Program**, PACER Center, Minneapolis, 1986. This publication provides case examples and guides regarding physical abuse, emotional abuse, physical neglect, and sexual abuse. It focuses on the special needs posed by children with handicapping conditions who are more vulnerable to abuse, more difficult to identify as victims, and for whom intervention is more complex. Despite significant progress in acquiring empirical, clinical, and statistical information about child abuse and despite a recognition of the magnitude of the problem, these gains are not equaled by progress in the identification, intervention, treatment, and rehabilitation of children and families, particularly those children who are handicapped. An extensive bibliography is provided including school curricula and a list of national, state, and local resources and services is included. An appendix includes statutes and reporting procedures. Copies are available for \$15.00 from: PACER Center; 4826 Chicago Avenue, South; Minneapolis, MN 55417. Tel. (612) 827-2966.

## **CATALOG OF ASSISTIVE DEVICES AVAILABLE**

A new "Special Needs" catalog has recently been published by Radio Shack. Many of the featured products are designed to aid persons with hearing or visual impairments such as amplifiers for telephones and "talking" time pieces. The "Special Needs" catalog may be obtained by writing: Radio Shack Circulation Department; 300 One Tandy Center; Fort Worth, TX 76102.

## **FEDERAL HIGHLIGHTS**

### **Federal Official Defends Mainstreaming**

At a recent national forum, Carol Inman, speaking on behalf of Madeline Will, Assistant Secretary of the U.S. Office of Special Education and Rehabilitation Services, defended the federal definition of Least Restrictive Environment (LRE) as it is applied to special education. She stated that, regardless of the disability, all children who are disabled must be mainstreamed when possible. For children who find it stressful to be educated in regular schools and classes, she said that a course

should be built into the curriculum to develop their "coping skills." She said the LRE may cause specialized, segregated schools to change their roles in the future to provide technical assistance or tutorial support in summer sessions or in part-time supplemental programs for mainstreamed students.

The phrase, LRE, appears in federal regulation P.L. 94-142, Education of All Handicapped Children Act. OSERS Assistant Secretary Will says the LRE means "a presumption in favor of placement in the regular educational environment--the regular classroom setting or the regular school setting" and that "to the maximum extent appropriate, handicapped children must be educated with children who are not handicapped."

### **Proposed Changes in the DD Act**

The Developmental Disabilities Act (P.L. 98-527) must be reauthorized by October 11, 1987. Some of the changes proposed by the Consortium for Citizens with Developmental Disabilities are:

- Adding individual and family empowerment as a new outcome of the act in addition to independence, productivity and community integration.
- Adding "applied technology" to the definition of terms and fundable services by Developmental Disabilities Councils;
- Modifying the terms used for federal priorities - community living, employment, child development and case management.
- Reinstating an optional priority area for Developmental Disabilities Councils;
- Adding individual support services to the definition of community living;
- Authorizing \$1 million to demonstrate and implement five to ten training programs for direct care workers and paraprofessionals in community agencies; and
- Raising the authorization level for each program.



# INFORMATION EXCHANGE

STATE  
SUPPLEMENT

## Developmental Disabilities Program

201 Capitol Square Building  
550 Cedar St.  
St. Paul, Minnesota 55101

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

Member of  
National Association of  
Developmental Disabilities  
Councils

June 1987

### ATTENDANT SERVICE ISSUES REACHING CRISIS PROPORTIONS, STUDY CONCLUDES

"Maintaining the current nonpolicy (about attendant services) will no longer work. . . . Personal assistance services in the United States are fragmented, lack coordination, are usually medically oriented, burdened with work disincentives, inequitably distributed, and delivered by personal assistants who are poorly paid. . . . The situation, in short, is reaching crisis proportions." This was the conclusion reached in a recently released report entitled, **Attending to America: Personal Assistance for Independent Living** (April 1987). The report was the result of a national survey of personal assistance services in the United States, conducted by the World Institute on Disability (WID), Berkeley, California.

Personal assistance involves assistance with tasks aimed at maintaining well-being, personal appearance, comfort, safety, and interactions within the community and society as a whole. "In other words," as further defined in the report, "personal assistance tasks are ones that individuals would normally do for themselves if they did not have a disability." WID recommends that personal care attendants should be renamed "personal assistance services" and not use the word care.

The need for community-based personal assistance services for independent living and the lack of a nationwide policy direction and mechanism for meeting that need has become an issue of major significance for people with disabilities of all ages who feel these services are critical to their ability to control their lives, said Simi Litvak, Principal Investigator of the study. For every person who is actually receiving community-based, publicly-funded personal assistance services, there are more than three people who need such services but who are not getting them, the study revealed. While there are an estimated 3.8 million people in this country who need personal assistance services, only 850,000 people are actually receiving such services.

The survey revealed that almost all of the service programs which do exist are inadequate. "Seldom do they offer the combination of personal assistance necessary to enable people who are disabled to function satisfactorily at home and in the community. Distribution of these programs is uneven across the United States, eligibility criteria vary widely, and direct

service providers are generally poorly compensated," Litvak stated in the report.

"What has emerged on a de facto basis as an outgrowth of existing federal programs is a medical model of personal assistance service delivery which is unnecessarily costly and inadequate," stated Litvak. "There is an ever growing population of older people needing attendant services and an increasing number of families unable to provide those services," he observed.

The report contains specific recommendations and action steps toward the establishment of a national personal assistance program for independent living. The recommendations were developed at an international symposium convened in 1985 by the World Rehabilitation Fund and the National Council on the Handicapped in conjunction with the World Institute on Disability. In addition, the World Institute on Disability recommended:

- 1) that meetings of federal and state policy makers with representatives of and advocates for people of all ages with all types of disabilities be convened and funded by the federal government. The purpose of these meetings would be to discuss the implications of this study and WID's recommendation to develop proposals regarding the development of a national personal assistance program for independent living; and
- 2) that the federal government study what other countries have done to incorporate personal assistance services into their national social service policy.

"It behooves policy makers to give serious consideration to this study and the recommendations it contains," Litvak concluded.

For more information and for copies of the report (including an **Executive Summary**), contact: World Institute on Disability; 1720 Oregon Street; Berkeley, California 94703. Tel. (415) 486-8314.

### PEOPLE WITH AUTISM ARE WORKING AND THRIVING IN ROCKVILLE, MARYLAND

In 1980, people laughed when told by the staff at Community Services for Autistic Adults and Children (CSAAC) that they intended to create real jobs in the community for adults with the most challenging

behaviors--autism. Even today many professionals who work with autism cannot believe what has been achieved in Rockville, a midsized town near the center of the state of Maryland where 35 adults with autism work in a variety of small manufacturing firms. The jobs include assembling machine parts, cutting and shaping copper tubing, welding, binding printed booklets and books, and recycling industrial materials.

CSAAC is a private, nonprofit organization which operates a school, adult residential program, and adult vocational program. The vocational program began out of an emergency need. At that time, CSAAC operated two group residences. The men in those residences had been terminated from their day activity placements. Several of these men had already experienced expulsion from other sheltered placements in the area due to behavior problems. The Maryland State Department of Health and Mental Hygiene, Mental Retardation Administration, funded CSAAC to develop day services for these adults to avoid institutionalization and remain in the CSAAC residential program.

All clients regardless of their behavioral disorders, functioning levels, or previous experiences are placed and trained in nonsheltered sites among workers who are nonhandicapped. The severity of the client's disability is accommodated by provision of adequate support services including enriched staff ratios and additional professional services within the integrated community work place.

Speaking about one of the workers, Roger Beach, who operates a printing firm, remembers that a few years ago, "He did have an occasional tantrum during the work week. But as time passed the tantrums ceased. I can't remember when he last behaved that way. Of course, I understand he still has tantrums at home but not here on the job."

According to Pat Juhrs, former Project Director, not one client had a successful job history prior to entry. Most had unsuccessful sheltered or day activity placements prior to entry. No one prior to their entry into CSAAC expected them to perform and be paid for meaningful work in private industry.

Today, the workers maintain a high record of punctuality and have earned reputations for methodically working at their tasks with accuracy and high quality. Over half (58 percent) of the clients who have been in the program for a minimum of one year have learned to travel to and from work without supervision. An additional six individuals are partially independent in use of public transportation to get to and from work. Over half of the clients, or 19 individuals, earn wages of minimum wage or better. Two individuals are completely independent at work with drop-in supervision, and six individuals are having gradual reduction of supervision moving to partial supervision at this time.

Another benefit has a very personal focus. After a period of employment, there have been marked

changes in behavior. Some talk more than before, are less withdrawn; they socialize with other workers in the lunch room and throw a Frisbee around during a break. Others have learned new job tasks of such sophistication that even Juhrs and other people at CSAAC are surprised.

A videotaped interview with Pat Juhrs, conducted while she was in Minnesota on June 3, 1987, will soon be released on a loan basis. Place requests with: Governor's Planning Council on Developmental Disabilities; 201 Capitol Square Building; 550 Cedar Street; St. Paul, MN 55101. Tel. (612) 296-4018.

A packet of publications about the CSAAC programs are available at the cost of \$5.00, payable to: Minnesota Association for Persons with Severe Handicaps; P.O. Box 1837 Pioneer Station, St. Paul, MN 55101.

## **TASH RESOLVES TO REDEFINE CONTINUUM OF SERVICES**

On November 5, 1986, in San Francisco, the Executive Board of the Association for Persons with Severe Handicaps (TASH) passed several resolutions which can have nationwide impact upon the quality of services for persons with disabilities. This article is the third in a series to share the TASH resolutions in their entirety:

### **Resolution on the Redefinition of the Continuum of Services**

Children and adults with severe disabilities require specialized and individualized services that traditionally have not been made available in typical school and other community environments. Instead, access to such services has been tied to categorical placements which increasingly isolate persons with disabilities from relationships with their family, peers, and other citizens. In the past, the concept of a continuum of services has been used to foster the notion that persons with severe disabilities must earn the right to lead integrated lives in the community. TASH believes, therefore, that a redefinition of the continuum is vitally needed.

The Association for Persons with Severe Handicaps believes that specialized and individualized services can be readily and effectively provided in integrated settings, and need not preclude opportunities to develop peer and other social relationships which are so critical to the achievement of full participation in society.

TASH further believes that effective methodologies and models which can be applied in integrated settings now exist, and that the focus of new significant and systematic research and development efforts should now be upon the development, implementation, validation, and dissemination of such alternatives to outdated practices which segregate persons with disabilities from their families, peers, and the community by requiring placement in handicapped-only and categorical grouped services and settings.

Therefore, TASH calls for a redefinition of the continuum of services which emphasizes the attainment of the following characteristics and components:

1. The provision of specialized staff, resources, and services to meet individual needs in the regular classroom, neighborhood school, home and family, and community program and setting;
2. The substantive training and retraining of personnel, both special and generic service professionals--to prepare them for providing instruction to a variety of heterogeneous groups of learners.
3. The systematic shifting of service delivery design and services away from a categorical, homogeneously grouped, and separate model to one which requires integration and thrives on a variety of grouping arrangements;
4. The philosophical and administrative merger of special and regular education and specialized and generic services into one service delivery system, evidenced by the integration of both professional staff and students; and
5. An unambiguous model of the Least Restrictive Environment which is marked without exception by integration into normalized community environments and proximity to family and peers who do not have disabilities and other citizens.

Furthermore, The Association for Persons with Severe Handicaps commits its resources and energies to support and promote such components of an integrated continuum of services through advocacy, dissemination, research, training, and program development in collaboration with consumers, colleagues, families, professional training programs, research centers, and community services.

For more information, contact: TASH; 7010 Roosevelt Way, NE; Seattle, WA 98115. Tel. (206) 523-8446.

## PUBLICATIONS

**A Guide for State Planning: For the Prevention of Mental Retardation and Related Disabilities**, President's Committee on Mental Retardation, 1987. This Guide provides an overview of important subject areas for each state and territory to consider in planning for the prevention of mental retardation and related disabilities. The President's Committee on Mental Retardation (PCMR) has accepted its responsibility to lead the national efforts in meeting the presidential goal to decrease the occurrence of mental retardation by 50 percent by the end of this century. Joining PCMR in this effort is a National Coalition on the Prevention of Mental Retardation with members representing the American Academy of Pediatrics, the American Association on Mental Deficiency, the American Association of University Affiliated Programs, and the Association for Retarded Citizens of the United States.

The Guide outlines the various intervention strategies that can effectively prevent the occurrence of mental retardation by more than 50 percent such as: proper nutrition, immunization, control and early treatment of disease, management of maternal illness, genetic counseling, identification and treatment of inborn errors of metabolism, high-risk pregnancy identification and care, early identification and treatment of learning problems, early childhood stimulation, child abuse prevention, childhood accident and injury prevention, and avoidance of harmful drugs and environmental chemicals. This publication provides the framework for the development of a written prevention plan in each state that is comprehensive and is specific to the needs of the individual state. Crucial to the planning process is the first step--to clarify the authority within the state and identify the responsible agency and/or person(s) who will take the leadership role in organizing and writing the plan.

Copies may be obtained by referring to DHHS Publication No. (OHDS) 87-21034 from: U.S. Department of Health and Human Services; Office of Human Development Services; President's Committee on Mental Retardation; Washington, DC 20201.

**Transition: A Report on Minnesota Youth with Disabilities**, Minnesota Department of Education, St. Paul, 1987. This report is intended to increase the awareness of policy makers, professionals, parents, and the general public regarding the current status of Minnesota's efforts to assist students and families to make a successful transition from school to work and community living. Stressed throughout the report is the importance of family involvement, interagency cooperation, and effective collaborative planning for quality educational programs that address the total needs of youth with disabilities.

The report is presented in four sections. Part I discusses the roles and responsibilities of education and other community service agencies in addressing the lifelong needs of people with disabilities. Part II presents recent Minnesota studies that identify current issues and problems regarding the transition of students to postschool employment and community living. Part III describes Minnesota's progress to date in strengthening transition services. Part IV discusses future state and local initiatives needed to improve transition services and interagency planning efforts. For copies of the report, contact: Interagency Office on Transition Services; Minnesota Department of Education; 800 Capitol Square Building; 550 Cedar Street; St. Paul, MN 55101. Tel. (612) 296-4163.

## 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.**

**Express Yourself: Communication Disabilities Need Not Be Handicaps**, Peg L. Johnson, Richfield, Minnesota: Pegijohn, 1987. This book started out as a college research project by the author and ended up as a full-blown publication. The book examines how individuals with various types of communicative disorders, as a result of physical impairments, are currently achieving various degrees of self-expression through the use of electronic augmentative communication aids. It examines the effect these aids have had on their lives, the types of aids that are available to meet various disabilities (seeing, speaking, hearing), and most importantly the mechanisms of selection and funding. Information was achieved through interviews with experts and with persons with disabilities, literature search, and contact with manufacturers and distributors of electronic communication aids. The author states that without a satisfactory means of augmentative communication, an individual's potential can never be fully realized. While these communication aids cannot eliminate an individual's disability, they can decrease the degree to

which the disability is a handicap. That's what this book is all about, says the author. The book may be purchased for \$9.95, plus \$2.00 postage and handling from Pegijohn, 6432 Fifth Avenue South, Richfield, MN 55423, or may be borrowed from the lending library, as listed at the top of this page.

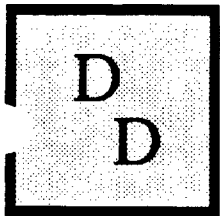
**Teaching Developmentally Disabled Children: The ME Book**, O. Ivar Lovaas, University Park Press, 1981. This book provides teachers and parents with an instructional program that shows how to help children with developmental disabilities to function successfully at home, in school, and in the community. Programs and exercises are presented step by step in plain language so instructors learn as they teach. Proceeding from easy to more complex behaviors, the program lays the groundwork for a continuing plan of development and improvement that proceeds at the child's own pace. As a result of following the programs presented in this book, the child does become more of a person, an individual, more of a me, says the author.

**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,  
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# INFORMATION EXCHANGE



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## METROPOLITAN COUNCIL DD PROGRAM NEWS

### 1987: QUALITY AND INTEGRATION

The past decade has brought so much change in the developmental disabilities service system that it is difficult for those who are concerned with the welfare of persons with severe handicaps to keep up with the newest information. Parents and suppliers of services are developing, testing and promoting so many new ideas that promise genuine integration in the community and improvements in the quality of life of individuals receiving the services. Some ideas are truly original. Others are creative adaptations of long-existent ideas. Among the latter is the concept of consumer-owned housing options.

Last month a conference on this topic was sponsored by the Minnesota Department of Human Services in cooperation with the Association for Retarded Citizens of Minnesota, the Association for Retarded Citizens of St. Paul and Creative Community Options. Bob Laux, President of Creative Management Associates in Portsmouth, New Hampshire presented a comprehensive overview of a value-based approach to establishing consumer or parental-owned housing on an individual basis or on a cooperative or corporate basis.

Mr. Laux suggested that the **values** which serve as the foundation to this approach are: "all people, with or without disabling conditions, need: an integrated place to live, community participation opportunities, access to necessary services, meaningful relationships and community acceptance." He stated that this type of housing ownership should build fiscal stability, reduce costs, create long-term residence, be easier to obtain, offer increased integration opportunities and should be owned by someone invested in the people who live there.

Mr. Laux also suggested an array of financing strategies, a list of steps in selecting housing, and suggestions for

securing program services as a separate segment of a total package. His presentation included slides showing an impressive variety of housing that has already been secured by his agency in the New England states.

The second session of the all-day conference presented agencies and their representatives who may be instrumental in making these new options available in the near future. Represented were the Department of Human Services, the Minnesota Housing Finance Agency, Common Space (a Minneapolis housing cooperative association), and a county human service agency as well as an attorney familiar with estate planning.

A new handbook, "**New Housing Options for People with Mental Retardation or Other Related Conditions**," was compiled as supplementary information to the conference by the Association for Retarded Citizens Minnesota and the Department of Human Services. It is available at \$3 per copy for ARC Minnesota members or at \$5 for non-members. For a copy send a check to the ARC Minnesota, 3225 Lyndale Avenue South, Minneapolis, MN 55408-3699.

### STATE LEGISLATURE CREATES SUPPORTED EMPLOYMENT TASK FORCE

The 1987 Minnesota Legislature passed a bill creating a task force to review and make recommendations regarding the appropriate roles of development achievement centers and sheltered workshops in providing supported work opportunities to people with disabilities. The task force will include representatives of the legislature, sheltered workshops, developmental achievement centers, county governments, the state Departments of Human Services, Jobs and Training and Education, the State Planning Agency, advocacy organizations and the Minnesota Supported Employment Project Advisory Committee.

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.

The task force will review and make recommendations to the Legislature and affected state departments by February 1, 1988, on the following:

- The role and function of developmental achievement centers, sheltered workshops and other services providing employment to persons who are severely disabled;
- Mechanisms for identifying and placing clients in appropriate services;
- Current and recommended funding methods for developmental achievement centers and extended employment programs and the relationship between funding and placement of clients;
- Current regulations and program standards including accountability requirements and outcome measures, including recommendations for common standards for all similar programs;
- Improved ways of providing employment services to all disabled persons regardless of the severity of their disabilities, including persons not currently receiving services through existing programs; and
- The need and scope of demonstration projects to determine how existing funding can be consolidated or unified to expand community-based/supported employment opportunities for persons with severe disabilities and whether specific rule waiver authority is required to accomplish this purpose.

## **EMPLOYMENT OPPORTUNITIES**

### **Executive Director**

AccessAbility, Inc. (formerly Cerebral Palsy Center, Inc.) is seeking candidates for the position of Executive Director. AccessAbility, Inc. is a nonprofit organization, fulfilling the needs of the community through eight major service programs, including preschool, community-based employment, work activity, production services and adult socialization. AccessAbility, Inc. has a budget of \$3.7 million, a staff of sixty and several hundred program participants.

The Executive Director reports to the Board of Directors. Responsibilities include directing the programs and services provided by the organization, operational planning, long range strategic planning, personnel, public relations, and fund raising.

The qualified candidate should have 10 or more years experience managing a social service or business organization. Strong management and communication skills are a must. The qualified candidate should have a bachelors degree (Masters preferred).

Applications including salary requirements should be sent to: Elaine Maffitt, AccessAbility, Inc., 360 Hoover Street NE Minneapolis, MN 55413. Since this opening was announced June 11, please call Elaine at (612) 331-5958 to see if applications are still being accepted.

## **RESOURCES/SERVICES**

### **Mothers' Support Group**

The Spina Bifida Association of Minnesota has a support group for mothers of children with this disability. Meetings are held the last Tuesday of each month at 1 p.m. at Shriners Hospital in Minneapolis. Children are welcome to attend with the mothers. If you wish to be contacted about the meeting or to get more information, call Kathy Lohmer (612) 439-6818 or Mary Richards (612) 426-4172.

### **Exercise Tape**

A specially designed program for persons with physical limitations is available on a videocassette. "Reach for Fitness: Special Exercises for the Physically Challenged," with Richard Simmons, costs \$14.95. It is distributed by Karl-Lorimar Home Video; 17942 Cowan; Irvine, CA 92714; P.O.P. Hotline: 1-800-624-2694.

### **Accessible Skyway Addition**

A new and accessible ramp has been opened in the Minneapolis skyway system connecting the Northstar Center and the 607 Marquette Building.

### **Supported Employment Videotape**

A new videotape, "Richard and Donna: A Little Bit of Faith," is available for lending, free of charge, from the Minnesota Supported Employment Project. The 12-minute tape focuses on the supported employment setting for two people with severe disabilities. It is designed as a marketing tool for anyone promoting supported employment to community business groups and would be appropriate to show at meetings such as chambers of commerce, Kiwanis and Rotary groups. To obtain the tape, call the Project office, (612)296-5629 or (800)328-9095, with a request including date to be shown and intended audience.

## **REQUESTS FOR ASSISTANCE**

### **Volunteers Needed**

- \* The Association for Retarded Citizens Suburban needs volunteers for its Library Task Force. Task force members will be asked to visit their local school's library to list and critique information that is available on the subject of mental retardation. There will be one meeting to develop procedure and tasks, then members will work independently.

Please call if you wish to help: Marianne; ARC Suburban; (612) 431- 3700.

Someone is needed to drive an adult camper from Cottage Grove to Camp Eden Wood in Eden Prairie on Sunday, July 19 and back from camp on Friday, July 24. Call Lori Perryman; ARC Suburban; (612) 431-3700.

## FOR YOUR INFORMATION

- \* **Handicapped Parking** law amendments were passed this year, raising the penalty to between \$100 and \$200 for illegally using a handicapped parking space. They also change the process to ensure that all new certificates and plates go only to disabled drivers; refine the eligibility requirements and provide for a \$500 fine for fraudulently using plates or certificates.
- \* **Hearing Impaired Access** to communications services will dramatically improve, by virtue of a new TDD assistance plan whose revenue is derived from a \$.10 surcharge from regular phone customers. The program will provide access to the more than 39,000 hearing- impaired persons who now have no access to phone services. A third-party relay system would also be established to reach businesses and agencies with no TDD service.
- \* **Metro Mobility Safety Standards** will be upgraded by a new set of operating standards put in place for special transportation services, a response to Metro Mobility's new private provider setup.
- \* **A Shoppers Guide** is now available in the office of The United Handicap Federation. It has been prepared by the Tele-Consumer Hotline. A complete set, including a Braille edition, lists what telecommunications equipment is available, from which companies, and what the listed prices are. The lists also state which companies repair the equipment. Prices can differ by as much as \$100. Please come in and make use of this guide. Recent changes in sales and lease prices of Northwestern Bell equipment announced April 9, make it especially important to compare what is available and at what cost.

UHF is also collecting data and catalogs for equipment and construction adapted for accessibility. There is a phenomenal amount of literature available, much of it with good information. UHF is located at 1821 University Avenue; Suite 284-South; St. Paul, MN 55104. Call: (612) 645-8922 (V and TTY).

### \* Accessible National Park List

"Camping in the Nation Park System" lists accessible campgrounds. Send a check for \$1.50 to:

Supt. of Documents; U.S. Government Printing Office; Washington, D.C. 20402. For more information on camping, write: The Committee for the Promotion of Camping for the Handicapped; 2056 South Buffalo Road; Traverse City, MI 49684.

### \* Skills For Life Newsletter

Pillsbury House in Minneapolis has scheduled a number of classes and events for adults with handicaps for the summer quarter. To receive a copy of the schedule request their summer newsletter, "Skills for Life." Pillsbury House; 3501 Chicago Avenue, S.; Minneapolis, MN 55407; (612) 824-0708.

### \* New Federal Pamphlet on Civil Rights

The U.S. Department of Education has a new handbook that outlines the rights of people with handicaps under a civil rights law. The 14-page pamphlet, "Handicapped Persons' Rights under Federal Law," spells out their rights under Section 504 of the Rehabilitation Act of 1973. It includes the addresses and telephone numbers of 10 regional civil rights offices where people can file discrimination complaints. It explains the responsibility that schools, colleges and other recipients of federal aid have to make their programs accessible to the handicapped. It also explains the protections people with handicaps have on the job and in health, welfare and social programs. A free copy of the handbook in English or Spanish is available by calling (202) 732-2075 or writing Fred Tate; Office for Civil Rights; U.S. Department of Education; 330 C St. S.W.; Washington, D.C. 20202.

## RECREATION/LEISURE ACTIVITIES

The ARC of St. Paul is now offering a social/recreational program for older adults with mental retardation through the Kellogg Club. The program is offered on Monday nights from 3:00 p.m. to 8:30 p.m. Membership fees will be \$1.50 per month or \$18.00 per year.

This program, known as "Seniors Night," will offer individuals over the age of 45 a chance to get together with their peers in a relaxed environment. Program participants will have access to a gameroom with a pool table, foosball, air hockey and video games; an art room with limited art supplies; and a lounge with reading materials, quiet games, a VCR, and comfortable couches. Participants will be able to choose from a variety of activities ranging from community outings to quiet reading in the lounge. For more information: ARC/St. Paul; 65 E. Kellogg, Suite 437; St. Paul, MN 55101; (612) 224-3301.

## CONFERENCES/WORKSHOPS

### August 31, 1987

*"Beyond Community Services: Toward Full Community Participation."* The American Association on Mental Deficiency (AAMD) will sponsor this workshop as a pre-conference event of the Minnesota Organizations. Key speakers include: John McKnight, Dave Witherow, Beth Mount and Tom Kohler. The conference runs from 9 a.m. to 4 p.m. with an AAMD business meeting at 4:15 p.m. Fees are \$25 for members and \$30 for non-members. To register: Mary Ann Stevenson; 1555 118th Avenue NW; Coon Rapids, MN 55433; (612) 754-2505.

### August 31, 1987

*"Leadership by Design: Make Your Style Work for You."* Another pre-conference workshop is being presented by ETC by Design. Keynote speaker is Mary T. Maher, Ph.D. Cost is \$30 including lunch. For more information or to register: ETC by Design; 1555 118th Avenue N.W.; Coon Rapids, MN 55433; (612) 724-2505.

## FEDERAL HIGHLIGHTS

### New Leaders for Key Subcommittees

The shift in the Senate from a Republican majority to a Democratic majority meant that Senator Lowell P. Weicker (CT), a leading advocate for individuals with disabilities, had to step down as Chairman of the Subcommittee on the Handicapped. Senator Tom Harkin, Iowa, who replaces Weicker as Chairman of the Handicapped Subcommittee, is new to the Subcommittee but is expected to share many of Weicker's concerns on issues affecting persons with disabilities. Senator Harkin has appointed Robert Silverstein to be the staff director of the Subcommittee.

A major agenda item of the Subcommittee will be the reauthorization of the various programs under the Developmental Disabilities Act. The Subcommittee has the responsibility of ensuring quality residential and community services for individuals with disabilities. The Subcommittee also has primary jurisdiction over vocational rehabilitation and special education programs.

In the House, Representative Pat Williams (MT) has stepped down as Chairman of the Select Education Subcommittee. Representative Major Owens (NY) is the new Chairman of the Subcommittee. Maria Cuprill is the new staff director. Ms. Cuprill, a long time aide to Representative Owens, is sensitive to the fact that children with handicaps are among the most vulnerable population to suffer abuse and neglect to and the programmatic links between children with handicaps, child abuse, and family violence. This is an important issue this year with the reauthorization of the Child

Abuse Prevention and Treatment Act on the top of the Subcommittee's agenda. The Subcommittee also has primary jurisdiction over vocational rehabilitation and special education programs.

### Federal Parking Legislation Proposed

Senator John Kerry (MA) has introduced S. 550, Traffic Safety for Handicapped Individuals Act. The purpose of the legislation is to enable motorists with handicaps to park more easily and safely as they travel from state to state. Currently, there is no national, uniform parking system and despite federal efforts, a number of states still fail to recognize the symbols for the handicaps. S. 550 will adopt the International Symbol of Access, provide for the issuance of license plates displaying the symbol, provide for the issuance of removable windshield placards, and ensure that licensing fees or vehicle registration used to transport handicapped individuals do not exceed other vehicle charges. If the state does not comply with the new law, its highway safety program and funding will not be approved. S. 550 has been referred to the Senate Committee on Commerce, Science, and Transportation. A companion bill, H.R. 1442, has been introduced in the House by Representative Sam Gejdenson (CT).

### New Tax Benefits

The Tax Reform Act of 1986 contains several provisions which are of interest to persons with disabilities, their employers, and businesses which can expand the customer bases by making the sites accessible. For example, one provision of the Act extends permanently a tax deduction of up to \$35,000 for businesses for the removal of architectural and transportation barriers. Another amendment permits a disabled employee to deduct the full cost of attendant care and other services necessary to enable the employee to work. This and other pertinent information is contained in the brochure, Tax Reform Act of 1986, which is available from the National Easter Seal Society, 2023 West Ogden Avenue, Chicago, IL 60612. The Paralyzed Veterans of America (PVA) also has available a brochure called The Tax Advantages of Section 190 which describes the general provisions and invites businesses to request more information from them at PVA, 801 Eighteenth Street, NW, Washington, D.C. 20006.



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National Association of  
Developmental Disabilities  
Councils

July 1987

### IS SUPPORTED EMPLOYMENT SERVING THOSE WITH SEVERE HANDICAPS? THE MEDICAID DISINCENTIVE

According to Frank Laski and Bonnie Shoultz in an article *Supported Employment: What About Those in Medicaid Funded Day Treatment and Day Activity Centers?* in the May issue of **Word from Washington**, Federal funding and administration of the Medicaid Program make it a virtual certainty that states utilizing Title XIX (Medicaid) funds for day programs (such as Minnesota and several other states) will continue to exclude adults with severe handicaps from vocational services including supported employment.

"In the last five years, supported employment has moved from an exciting series of university-based experiments to a major federal demonstration initiative by the Office of Special Education and Rehabilitative Services (OSERS) and the Administration of Developmental Disabilities to become a real, practical and widely accepted employment option for people with severe disabilities," Laski and Shoultz observed. The latest amendments of the Rehabilitation Act (P.L. 99-506) designated supported employment as a legitimate vocational rehabilitation outcome and created a state formula grant program for supported employment. These amendments defined supported employment as competitive work in integrated work settings for individuals with severe handicaps for whom competitive employment has not traditionally occurred and who because of their handicap need intensive, ongoing support services to perform such work.

"At this time," Laski and Shoultz continued, "there is no way of knowing how many individuals in supported employment (have not been served by the) rehabilitation system . . . or to what extent there has been diversion of supported employment concepts and resources to serve a traditional severely handicapped vocational rehabilitation population. However, it is not too early to respond . . . that current and planned programs of supported employment are missing the intended population of individuals **with the most severe handicaps** (emphasis added)." The authors warn that if the expanding supported employment resources are not used to support those individuals with the most severe handicaps, this population will continue to be excluded from vocational options.

Currently, many persons with severe disabilities are

being served in variously called day treatment centers, day activity centers, or developmental achievement centers, served "not so much based on particular needs but based on their exclusion from employment oriented models."

There are currently eighteen states (including Minnesota) that fund day programs under the Title XIX program. Except for a handful of persons deinstitutionalized under Title XIX Home and Community Based Service waivers, the Health Care Finance Administration's interpretation of Title XIX prohibits Medicaid reimbursement for vocational training and most prevocational services. "Thus," concluded Laski and Shoultz, "in states with a high investment in Title XIX funded day programs, the vocational exclusion is likely to (1) cause states to define adult services for persons with severe handicaps strictly as nonvocational or prevocational services and (2) move implementation of supported employment away from its intended population, individuals with severe handicaps."

According to David Braddock (University of Illinois at Chicago), federal Title XIX expenditures in day programs climbed from \$3,989,000 in 1977 to \$38,600,000 in 1981; by 1986, the federal government was spending \$101,821,000 on Title XIX funds in day programs, or an increase of 163 percent over the last six years.

Minnesota is among the top users of Title XIX funds for day programs:

#### FY 1986 EXPENDITURES

New York	\$ 22,676,000
New Jersey	\$ 11,322,400
Illinois	\$ 10,000,000
<b>Minnesota</b>	<b>\$ 9,116,900</b>
Massachusetts	\$ 8,300,000
Washington	\$ 5,337,000
Michigan	\$ 4,838,000

Laski and Shoultz observed that every state which uses Title XIX funds for day programs has developed a continuum model of services which relegates those with the most severe disabilities to sheltered, segregated, non-vocational settings. The authors then concluded, "Health Care Financing Administration policies throughout the years, effectively writing rehabilitative services out of Title XIX, have seriously restricted the habilitation of persons in Medicaid funded programs. The continued exclusion of Title XIX funded program recipients from supported employment will not only

adversely affect the life changes of those individuals with severe handicaps, but will seriously impede the implementation of supported employment in those states that opt to retain Title XIX day program dollars."

**Word from Washington** is published by United Cerebral Palsy Associations, Governmental Activities Office, 1522 K Street, NW, Suite 1112, Washington, DC 20005. Tel. (202) 842-1266.

## **TASH PASSES RESOLUTION ON EXTENDED SCHOOL YEAR PROGRAMMING**

On November 5, 1986, in San Francisco, the Executive Board of the Association for Persons with Severe Handicaps (TASH) passed several resolutions which can have nationwide impact upon the quality of services for persons with disabilities. This article is the fourth in a series to share the TASH resolutions in their entirety:

### **Resolution on Extended School Year Programming**

WHEREAS: Public Law 94-142 guarantees children with handicapping conditions the right to a free appropriate public education;

WHEREAS: Public Law 94-142 designates the school the lead agency for identifying children's needs and coordinating I.E.P. programs;

WHEREAS: The Individual Education Plan (IEP) must include a statement of the child's needs, long and short-term instructional goals, related services, extent of participation with persons who do not have handicaps, and the IEP should cover a full calendar year;

WHEREAS: In litigation, the limiting of special education and related services on the basis of a 180-day school year has been found to be a violation of Public Law 94-142;

WHEREAS: We believe that the acquisition and generalization of many crucial community, vocational, domestic, and recreational/leisure skills are facilitated by year-round programming;

WHEREAS: We believe that the acquisition and maintenance of such skills is necessary to ensure successful integration into the community by children with disabilities when they reach adulthood; and;

THEREFORE BE IT RESOLVED: The Association for Persons with Severe Handicaps urges local and state educational agencies and community agencies to include year-round programming as part of the range of educational opportunities for children with handicaps. These programs should be functional, integrated and meet individual needs.

For more information, contact: TASH; 7010 Roosevelt Way, NE; Seattle, WA 98115. Tel. (206) 523-8446.

## **INPUT FROM PARENTS REQUESTED: PREPARING HEALTH CARE PROFESSIONALS**

Patricia Taner Leff, M.D., Brooklyn, New York, is currently compiling data for a multidisciplinary book aimed at helping student health care professionals to

understand and appreciate the psychosocial needs of children with chronic illnesses and/or disabilities and their families. Ideas and experiences from parents will be helpful in developing a chapter on "Preventing 'Parent Abuse': Guidelines for Listening to Parents. Some suggested topics might include: 1) helpful encounters within the health care system; 2) destructive or painful experiences with health care professionals; 3) what you would like "to say" to health care professionals; and 4) specific concerns about the way medical information (e.g., diagnosis, prognosis, the need for further tests or procedures) has been communicated to parents. Strict rules of confidentiality and anonymity will be upheld. Write to: Ms. Patricia Taner Leff, M.D., 488 Second Street, Brooklyn, New York 11215.

## **GILLETTE CHILDREN'S HOSPITAL TO FILL VOID LEFT BY DISCONTINUED DEVELOPMENTAL DISABILITIES PROGRAM**

Although the Developmental Disabilities Program at Gillette Children's Hospital was discontinued on May 29, 1987, evaluation and clinical services for young people who have difficult and multiple disabilities will continue to be provided through other programs. For information about optional evaluation services, contact Flossie Rafferty, admitting coordinator, at (612) 291-2848, extension 250.

## **PUBLICATIONS**

**Report to the President: Citizens with Mental Retardation: Equality Under the Law**, President's Committee on Mental Retardation, 1987. The content of this report includes the contribution of participants, who were invited experts in the field of law and mental retardation, attending the Second National Conference on Legal Rights for Mentally Retarded citizens held March 14-16, 1985. The report also contains selected resolutions passed by the membership of the President's Committee on Mental Retardation, relating to the subject of law and mental retardation. It addresses recent and current legal issues and needs, including the role of local and state government, least restrictive environment, self-advocacy, right to survival, and family and community living. Among several strategies for future development, is a strong stance regarding community integration of persons with mental retardation:

The issue of community integration would benefit from redefinition. People are born integrated in their families. The issue is not whether individuals with mental retardation should be integrated in the community, but rather whether they ever ought to be segregated from it.

Copies of the report may be obtained from: President's Committee on Mental Retardation; Washington, D.C. Tel. (202) 245-7634.

**Supported Employment: Federal Policies and State Activities Related to Integrated Work Opportunities for Persons with Developmental Disabilities**, National Association of State Mental Retardation Program Directors, 1987. Supported employment has emerged as one of the most promising and exciting developments in the area of services to persons with severe handicaps. This new publication attempts to demonstrate the linkages between policies governing federal and state programs which have a bearing on whether persons with severe disabilities are employed. Part One provides a summary of recent federal legislation and demonstrates a variety of ways that federal policies impinge on efforts at the state and local level. Part Two summarizes the current activities of state mental retardation/developmental disabilities agencies in the area of supported employment, emphasizing new and innovative programs, collaboration with other state agencies, and comparative costs of day services versus supported employment. A list of contact persons in each state is also provided. Cost: \$20.00 per copy, made payable to: NASMRPD; 113 Oronoco Street; Alexandria, VA 22314. Tel. (703) 683-4202.

**Prevention Update** is a newsbrief publication that summarizes current information about various aspects of preventing disabilities, focusing on a single topic in each issue. This series is from the National Coalition on Prevention of Mental Retardation, which is developed jointly by the Maternal and Child Health Consortium Project of the American Association of University Affiliated Programs and the National Coalition. Contact: AAUAP, 8605 Cameron Street, Suite 406, Silver Spring, MD 20910. Tel. (301) 588-8252.

#### **MASTER'S PROGRAM IN SUPPORTED EMPLOYMENT OFFERED**

A Master's program in Supported Employment is available at the Training and Research Institute for Adults with Disabilities, sponsored by the Division of special Education and Rehabilitation at Boston College, Boston, Massachusetts. This 36 credit program is intended for students interested in expanding their skills in designing, implementing and monitoring integrated employment programs for persons with severe disabilities. For applications or further information, contact: William E. Kiernan, Ph.D., Director; Training and Research Institute for Adults with Disabilities; Boston College; Chestnut Hill, MA 02167. Tel. (617) 552-4180.

#### **CONFERENCES/WORKSHOPS**

**A Lecture Series on Epilepsy** is scheduled on the first Monday evening (7:00 to 9:00 p.m.) of each month from July through December. The lectures will be presented at the St. Paul Room, Bethesda Lutheran Hospital, 559 Capitol Blvd, St. Paul, Minnesota. Dates and topics are as follows:

July 6	What Is Epilepsy? An Overview
August 3	Communication: Getting the Response We Want from Others

September 14	Interaction of Drug Combinations
October 5	Medical Aspects: An Overview
November 2	Lifestyles Management: Adapting to Epilepsy
December 7	Christmas Party Potluck

For more information, contact: Logan Fredrick, Epilepsy Foundation of Minnesota, 672 Transfer Road, St. Paul, MN 55114. Tel. (612) 646-8675, or (800) 292-7932, toll free.

#### **July 11, 1987**

**Parent Case Management Training.** The Association for Retarded Citizens Suburban (ARC), through grants from The Governor's Planning Council on Developmental Disabilities and the Emma B. Howe Memorial Foundation, is implementing a Parent Case Manager Program. The intent of the program is to empower parents and/or guardians in Dakota, Scott and So. Washington counties to act as Case Managers for their children with developmental disabilities. One aspect of the program is to train parents of sons and daughters with developmental disabilities about pertinent issues. An upcoming training session featuring Lois Cranston, a teacher consultant in the Anoka School District, will focus on Teaching Strategies. The session will be held Saturday, July 11, 1987 from 9:00 a.m. to Noon at 14451 County Road 11, Burnsville, MN.

Registration is free to ARC members and \$10.00 per family for non-members. For further information, contact: ARC Suburban, 14451 County Road 11, Burnsville, MN 55337. Tel. (612) 431-3700.

#### **August 7-9, 1987**

*"Passages and Portages...Into the Mainstream"* is the theme of the 1987 Association for Retarded Citizens convention, to be held at Winona State University in Winona. Anne Donnellan, Ph.D., Associate Professor at the University of Wisconsin at Madison, will speak on Friday, August 7th. Her topics will be "Why Behavior Problems Occur: The Communicative Function of Behavior" and "What We Can Do: Positive Approaches to Behavior Needs. Saturday's keynote panel will be "Welsch Revisted: Scenes from the Past, Glimpses of the Future." Forty workshops are planned on topics of interest to families, professionals, and adults with mental retardation. For further information, contact ARC Minnesota, 3225 Lyndale Avenue South, Minneapolis, MN 55408 or call (612) 827-5641 or Toll Free 1-800-582-5256.

#### **September, 14-16, 1987**

**The Second Annual National Community Integration Forum: Future Images for People with Severe Disabilities** will be held at Inn on the Park, Madison, Wisconsin. It is intended for those committed to full community integration of persons with developmental disabilities. For more information, contact: New Concepts; P.O. Box 376, Middleton, WI 53562.

## 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.**

**Providing Psychological and Related Services to Children and Adolescents: A Comprehensive Guidebook**, S. Striefel and P. Cole, Brookes Publishing Company, 1987. The intent of this guidebook is to provide a single comprehensive source of procedures and practices on how to provide psychological and related services to children and adolescents. Based on experiences at the Developmental Center for Handicapped Persons at Utah State University, the book specifically delineates information, procedures, and considerations relevant to setting up, operating, and working in a clinic for to children and adolescents, while simultaneously identifying the general goals, philosophy, and operating procedures for such a clinic. The guidebook serves a broad audience, human service professionals, paraprofessionals, parents, and especially students enrolled in courses concerned with providing psychological and related services. Administrators are given numerous ideas for fulfilling responsibilities in overall operations and in specific areas of policy, including legal and ethical concerns. Clinic operations

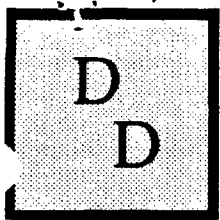
are streamlined so that staff can concentrate on valuable counseling services.

**Achieving the Complete School: Strategies for Effective Mainstreaming**, D. Biklen, Columbia University, 1985. This book describes the principles and strategies that have been tried and proven effective when integrating children with disabilities in school settings. Case examples illustrate the complexities of integration. Each element is based on two research projects that were carried out simultaneously over three years. Urban, suburban, and rural school districts were represented, as well as a range of types of disabilities, including preschool, elementary, and secondary levels. The essence of the book is the experience and lessons to be learned from integration as observed in America's schools. The forward written by Burton Blatt encourages people outside of special education to also read this book, saying, In (this book) there is a lesson for everyone--that all people are valuable, and that our lives are enriched and fulfilled as we live by that wisdom.

**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

**RECEIVED**

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## **METROPOLITAN COUNCIL DD PROGRAM NEWS 1987: Quality and Integration**

Medicaid reform legislation will be introduced in the U.S. Senate on September 10, 1987 by its chief author, Senator John H. Chafee (R-RI). The bill, the MEDICAID HOME AND COMMUNITY QUALITY SERVICES ACT OF 1987, "would amend Title XIX of the Social Security Act to assist individuals with a severe disability in attaining or maintaining their maximum potential for independence and capacity to participate in community and family life, and for other purposes."

The bill offers a wider range of residential and other support arrangements that may be funded under this entitlement than is currently allowed. It reflects emerging trends in many states that indicate institutional placements are decreasing and more individualized alternatives are being established. These amendments limit growth in federal funds for institutional services but have no time schedule for closing or phasing down of institutional facilities. The bill incorporates a comprehensive framework for monitoring quality. This is a summary of major provisions:

### **Eligibility**

- People with severe disabilities who meet the federal SSI test and who were disabled prior to age 22 will be eligible.
- Children under 10 living at home will be included by addressing deeming issues and equality of income standards for institutional or community living arrangements.

### **Services**

- Services will be available to persons living in family homes, or, as defined, foster homes or community living facilities.
- Services must be based on an Individual Habilitation Plan and coordinated by an independent case management system.
- States may offer the following services under their state Medicaid plans: case management; individual and family support services; protective intervention;

habilitation services; occupational therapy; physical therapy; speech therapy; nonaversive behavior intervention therapy; diagnostic and assessment services; personal assistance and attendant services; home-maker services; adaptive equipment, vehicles and housing; home health services; dental services; rehabilitation services; specialized vocational services (including prevocational and supported employment services); respite care; crisis intervention; specialized training for families and caregivers; special transportation services; personal guidance, supervision and representation; preventive services; and such other services proposed by a state and approved by the Secretary.

- States must provide case management; individual and family support services (including respite care); specialized vocational services; Protection and Advocacy services; and protective intervention services.
- Community Living Facilities are limited to a maximum of three times the average family household size in the area as determined by the census.

### **State Requirements:**

- The state must limit the amount of federal funds claimed for services provided to eligible persons in Medicaid certified facilities (ICF/MRs, ICFs, SNFs) with 16 beds or more. The limit is the level of funding for those services in the year of enactment. Provisions for additional expenditures in limited circumstances will be included: for years with inflation over 6% and for situations where there are increased costs due to a look behind survey, if the corrections necessary are tied to a phase-down plan.
- The state must develop a five-year implementation strategy which is updated annually to address specific requirements in the bill. There must be public involvement, including the Developmental Disabilities Council, in the development of and updating of the state implementation strategy.
- In the state implementation strategy, some of the concerns the state must address include: a multi-year strategy for systematically expanding community services and increasing the proportion of total federal and state Medicaid dollars for family and community support services over congregate care services; methods to be

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.

used to protect the interests of employees from institutions; policies and procedures to assure that all personnel have received preservice education and/or training; methods to assure that every service agency maintains written personnel policies and provides inservice training and continuing education to service personnel; an assurance that all provider agencies have access to needed technical assistance services; and that all eligible persons have access to case management which must be independent of any agency or program providing day and/or living arrangement services to them.

#### **Quality Assurance**

■ The state must set forth an implementation plan that includes its methods and procedures for instituting and maintaining a comprehensive, integrated quality assurance system. The plan must include at least the following: standards governing each element of community and family support services; methods and procedures for licensing and certification; procedures for an annual independent third party evaluation of services including measurement of consumer outcomes; an annual assessment of consumer satisfaction; a services environment assessment with family participation; methods for correcting deficiencies; provision of training and technical assistance; a system of penalties for non-compliance; and procedures for continuity of services when a provider fails to continue. In addition, the bill provides for the right of any party adversely affected by a violation of the Act to seek injunctive relief in federal court, including the recovery of attorneys' fees, under specified circumstances.

■ The bill establishes a set of service principles on which the state standards must be based. The Senate Committee on Finance will have major influence on the bill. Senator David Durenberger of Minnesota is a member of this important committee and is interested in learning how this bill is viewed by those concerned about persons with severe disabilities. You may write or call: Senator David Durenberger; 1020 Plymouth Building; 12 South Sixth Street; Minneapolis, Minnesota 55402; (612) 370-3382 or 154 Russell Senate Office Building; Washington, D.C. 20510; (202) 224-3244.

#### **REQUEST FOR PROPOSALS**

The Dakota County Division of Human Services is issuing a Request For Proposals to identify contractor(s) able to carry out community wide sectoral planning for two service areas:

**Area #1:** Services to persons with mental retardation and related conditions.

**Area #2:** Services targeted to the early intervention/prevention of handicapping conditions in children.

**Scope of Proposals:** Individuals or organizations may submit proposals on one or both planning areas.

**Approximate Time Period for the Contract:** September through December (1987).

**Eligibility:** Individuals, or organizations with demonstrated experience in community wide planning and understanding of the area bidding.

**Funding:** Total of \$30,000 for both areas.

**Proposal Submission Date:** On or before 12:00 P.M. September 4, 1987.

Copies of the Request For Proposals are available on request by writing or calling: Joseph Schur, Planning Director; Division of Human Services; 33 East Wentworth; West St. Paul, MN 55118; (612) 450-2811.

#### **INTERNSHIP OPPORTUNITY**

**Human Services Administration--**Student with a variety of skills in human services administration is needed to provide staff support to the Minnesota Coalition on Caregiver Support Services, which is comprised of over 50 agencies and organizations concerned about the needs of caregivers and the lack of coordinated complete system support services, such as respite care. The purpose of caregiver support services is to provide relief to the primary caregiver from the daily responsibilities of caring for a disabled family member, thus preventing individual and family breakdown or institutionalization by relieving the stress resulting from giving continuous support and care to the person with disabilities residing with the family.

Duties may include: writing minutes of meetings, correspondence, news releases, and grant proposals; informing policy makers, such as legislators and county commissioners; and conducting needs assessment/research. Please submit resume to and/or call for more information from: Sue Abderholden, Executive Director; Association for Retarded Citizens Minnesota; 3225 Lyndale Avenue, South; Minneapolis, MN 55408; (612) 827-5641.

#### **EMPLOYMENT OPPORTUNITIES**

**Administrator/Program Director.** Full time Administrator/Program Director position open in Litchfield, MN at ICF-MR (15 bed facility) for adults. Minimum qualifications: Bachelor's degree in Social work, Psychology, Education or Sociology; three years experience in field of retardation one of which should be in administration, program development, personnel management or behavior modification; QMRP status desirable. Send resume and salary requirements by September 11, 1987 to Edwin Lentz, Board Chairman; 716 East 4th Street; Litchfield, Minnesota 55355; (612) 693-8246.

#### **REQUESTS FOR ASSISTANCE**

**Very Special Arts - Minnesota** is seeking people with experience in the arts and a willingness to bring enjoyment of the arts to people with disabilities. VSAM needs artists statewide who can serve as workshop leaders for one or more days. If any reader is interested in serving as an art consultant for VSAM, please call

Susan Harden, (612) 922-2928 or write to her at 5701 Normandale Road, Minneapolis, Minnesota 55424.

## ADULT FOSTER HOMES NEEDED

Scott County Human Services is recruiting individuals and families who can be licensed to provide quality foster care to adults who would like to live in a home setting. Currently two adults with mild mental retardation are interested in being considered for Adult Foster Care.

\* Jim is a quiet, reserved, pleasant gentleman in his mid-sixties who works three days a week as a volunteer at a Belle Plaine service organization and would like to continue with this work. He is in good health with some occasional minor medical problems and enjoys gardening, crafts, drawing, bike riding, social outings and trying new things. Jim can take care of all his personal needs but would benefit from companionship and the opportunity to gain confidence in his abilities.

\* Emma is a feisty, fun loving 72 year old woman who volunteers five days a week and would like to continue her involvement with this type of work. She has a diet-controlled, diabetic condition and also takes a medication for a respiratory condition. Emma is a whiz in the kitchen, enjoys gardening, sewing, needlework, crafts and all sorts of social activities. All of these combine to keep Emma quite independent in all areas of self-care and could greatly benefit from living with a caring family. The experience of a family will greatly enrich Emma's senior years.

If you are interested in becoming an adult foster care provider for Jim or Emma or in hearing more about the foster care program, please call Linda Plessner at (612) 445-7751, (612) 873-6615 or (612) 758-6263.

## RESOURCES/SERVICES

### \* BRAIN INJURY RESOURCE LIBRARY

The Josephine Kretsch Library is a non-profit organization helping other libraries meet the needs of families with brain-injured family members. The library works directly with librarians to make sure the full range of brain injury-related literature, including the latest research findings, is cataloged and available. It also provides in-library displays to inform the public and maintains a telephone hotline. Callers may order bibliographies and hard-to-find reference materials, and may subscribe to an update service which releases the latest research findings as they become available.

Funding for the Kretsch Library comes from private grants and donations. For more information: Josephine Kretsch Brain Injury Resource Library; 5034 Oliver Avenue North; Minneapolis, Minnesota 55430; Hotline phone: (612) 521-2266.

### \* NEW TRENDS IN MUSIC

Dr. Cecilia Schmitt, a consultant from the Mid-State Co-op in Little Falls published a book-tape kit, ***Music and Dance: A Program for Teaching Youth and Adults with Mental Handicaps***. The new curriculum was demonstrated at the North Central Music Educators Convention held last February. The curriculum is the first of its kind in the nation, and emphasizes functional skills. The book-tape kit was designed for use in the public schools. However, since it is so easy to follow, it can also be used by parents, parks and recreation leaders, aides and recreation therapists under the direction of a music specialist. The curriculum costs \$48.95 postpaid. It can be ordered by writing to the author at St. Francis Music Center; 116 S.E. 8th Ave.; Little Falls, Minnesota 55345. The author can be reached by phone at (612) 632-2981.

### \* ACCESSIBILITY PROGRAM

The Architectural Barriers Removal Program, within the City of Bloomington's Office of Special Services, is equipped to handle questions, complaints, and/or comments concerning accessibility for persons with physical disabilities at facilities/buildings within the City of Bloomington. Funds for the program are provided by the Bloomington City Council from its Community Development Block Grant allocation. To make an inquiry or place a complaint about a site in Bloomington, contact Cynthia Pudewell, Architectural Barriers Removal Program, at (612) 881-5811, ext. 320 (or 887-9677, TDD).

### \* MACLD INSERVICE PROGRAM FOR REGULAR EDUCATORS

"Help " How can I most effectively teach and support the learning disabled student in my mainstream class?" is the frequent request of regular education teachers. Now the Minnesota Association for Children and Adults with Learning Disabilities (MACLD) has an answer - **"Keymakers."** With funding provided by the Foundation for Children with Learning Disabilities, in New York, MACLD has developed a four-hour inservice package on curriculum modification and support techniques specifically designed for mainstream teachers, grades 4 through 6, with further adaptability for upper middle and junior high school teachers.

The multi-media inservice includes all necessary leader guides and instructional materials for conducting the inservice for regular education staff. The complete package - 30 minute videotape, audio tapes, leader manual and 11 participant manuals - cost \$295. For further information or to order, contact MACLD; 1821 University Ave.; St. Paul, MN 55104; (612) 646-6136.

### \* EMPLOYMENT INFORMATION

HELPLINE is sponsored by the Minnesota Department of

Employee Relations to provide information to all Minnesotans about state civil service jobs. Call (612) 296-6700 or toll-free for Greater Minnesota callers, 1-800-652-9747.

#### \* FREE LOAN VIDEO

*"Meeting the Challenge"* is a video (VHS) which portrays the abilities and needs of people who are blind and have multi-handicaps. The film shows how three people function independently at home and at work. For more information: American Foundation for the Blind; 15 West 16th Street; New York, N.Y. 10011; (212) 620-2037.

#### \* PEER SUPPORT PROGRAM

Minnesota's Centers for Independent Living (MCIL) sponsor a program in which people with disabilities are matched with volunteers who are disabled. The volunteers may be able to briefly visit their peers at home to discuss non-medical problems that are of concern to persons who are disabled. The Centers are looking for volunteers. A small stipend is available for volunteers but the program is free for the person for whom the match is made. For more information call the Center in your area: Metro Center (612) 646-8342; Rochester Center (507) 285-1815; Northeaster (Hibbing) Center (218) 262-6675; People, Too (St. Cloud) (612) 255-1882; Rural Enterprises for Acceptable Living (Marshall) (507) 532-2221.

#### FOR YOUR INFORMATION

#### \* VOTER ACCESSIBILITY GUIDE

*"Disabled Citizens at the Polls: A Guide for Election Officials"* is a 28-page illustrated manual published by the National Organization on Disability (NOD). Accompanying the manual is a "Disabled Voter Information Card" with several suggestions for cost-effective adaptations to make voting sites more accessible. Individuals may purchase the manual at cost, \$3.00, by sending a check to NOD; Washington, D.C. 20037. A copy is available for review only at the Metropolitan Council. Please call ahead at 291-6364 if you wish to see it.

#### \* JOB SUCCESS FAIR FOR SOUTH HENNEPIN COUNTY

The third annual JOB SUCCESS FAIR for persons with developmental disabilities will be held on Friday, October 9, 1987, from 9:00 a.m. until 11:00 a.m. at the Bloomington National Guard Armory, 3300 W. 98th Street (just east of France Avenue). This event will provide an opportunity for participants to meet employers, learn more about jobs in the south Hennepin community, and find resources available to assist with vocational training and placement. The fair is primarily geared towards students who are currently

receiving, or graduates who did receive, Special Education services. Participants may also attend mini-sessions on employment-related topics. The JOB SUCCESS FAIR is sponsored by the City of Bloomington's Office of Special Services with assistance from Community Education's Learning Exchange, the Bloomington Human Rights Commission and the Hennepin County Association for Retarded Citizens. For more information: Office of Special Services; (612) 881-5811, ext. 320 (TDD 887-9677).

#### \* PUBLICATION AVAILABLE ON TAPE

The "Connector," a publication of the Minnesota Council on Disability is available on cassette from the Minnesota State Services for the Blind. Call (612) 642-0502 or toll-free 1-800-652-9000.

#### \* MESSIAH CHOIR IN AMERICAN SIGN LANGUAGE

The Hearing Society of Minnesota invites members of the public to join its choir which is practicing now for the 1987 Christmas season. No signing skills are required (they will train); no singing skills are required (they will not train). Tuesday is practice night. Enjoy and bring joy. For more information: Ellen Fidalgo; Hearing Society of Minnesota, 2100 Stevens Avenue; Minneapolis, MN 55404; (612) 870-0321, V or TTY.

#### \* TEACHERS' GUIDE TO TEACHING INTEGRATIVE VALUES

"Accepting Individual Differences" and "A Curriculum to Foster Understanding of People with Disabilities," New York State Department of Education (1986). These curricula for elementary and secondary levels, respectively, teach positive attitudes toward individuals with disabilities. The first includes five flip books, teacher guides and a cassette tape. \$6.50. The secondary curriculum includes four books. \$6.00. Prepaid orders may be sent to New York State Education Department; Publication Sales Desk; Room 114 Education Building Annex; Albany, N.Y. 12234; (518) 474-3806.

#### \* FALL SERIES ADDRESSES FAMILY LIFE, DISABILITY

A lecture series for families of a child or adult with a disability will be conducted September 22 - October 27 by the Association for Retarded Citizens (ARC) of Hennepin County. The sessions will include information to assist families maintain a quality home life, obtain services best suited for their son or daughter and increase their abilities to make a difference. All interested persons are invited to attend some or all of the weekly sessions to be conducted at Edina Community Center, on successive Tuesdays, September 22-October 27, 7:30-9:00 p.m. Cost is \$5 per family per session for ARC members, \$7 for non-members. To obtain registration form, please call (612) 874-6650.



## CONFERENCES/WORKSHOPS

**September 18, 1987**

**"The Self-Esteem Model of Sexuality Education"** is a workshop sponsored by Planned Parenthood for professionals whose clients include people with mental retardation. Roger Mellot, M.A. Therapist and Consultant, will present the workshop at the Minneapolis YWCA; 1130 Nicollet Mall; Minneapolis, MN. The workshop will offer .6 CEUs and has a registration fee of \$50. For registration form or more information: Planned Parenthood of Minnesota; Department of Education and Training; 1965 Ford Parkway; St. Paul, MN 55116; (612) 698-2401.

**September 21-22, 1987**

**"Case Management: The Critical Connection"** is a conference that will be held at the Holiday Inn--Town Square in St. Paul, cosponsored by the Minnesota University Affiliated Program (UAP) for Persons with Developmental Disabilities and the Minnesota Department of Human Services. The keynote address will be presented by Debra M. Spitalnik, Ph.D., director of the UAP of New Jersey. For more information, contact: Dorothy Skarnulis, UAP, 6 Pattee Hall, University of Minnesota, 150 Pillsbury Drive, Southeast; Minneapolis, MN 55455. Tel. (612) 624-4394.

**October 15-17, 1987**

Association for Retarded Citizens National Convention will be held at the Washington Hilton in Washington, D.C. The convention theme is **"Capitalizing on Our Power."** For registration forms or more information call local ARC chapters or write: 1987 ARC Convention; ARC/District of Columbia; 900 Varum St. N.E.; Washington, D.C. 20017.

**October 29-31, 1987**

The Association for Persons with Severe Handicaps (TASH) will hold its 14th Annual Conference at the McCormick Center Hotel in Chicago, Illinois. The theme of the meeting is **"Back to the Future: Integration Revisited."** Workshops, panel presentations, and papers will be offered on community and school integration issues including residential, vocational, educational, and social/sexual development; infant and family issues; legal issues; nonaversive intervention techniques; self-advocacy; technology; and related services. Note that registration for parents of persons with severe handicaps is free. Conference packets may be requested from TASH; 7010 Roosevelt Way, Northeast; Seattle, WA 98115. Tel (206) 523-8446.

**October 30-November 1, 1987**

Epilepsy Foundation of American National Conference will be held at the Sonesta Beach Hotel in Key Biscayne, Florida. For registration forms or other information: Diane Lipsey, Conference Coordinator; EFA; 4351 Garden City Drive; Landover, MD 20785; (301) 459-3700.

## PUBLICATIONS

**"Aging and Mental Retardation: Extending the Continuum,"** AAMD Monograph No. 9 by Marsha Mailick Seltzer and Marty Wyngaarden Krauss. The monograph provides new descriptive data on the characteristics of older persons with mental retardation that was collected in a national study. It contains a review of the literature and of current institutional and community-based day and residential programs, factors in programs that appear to be effective, and information on the role and structure of informal support networks. It discusses new directions in policy-making, service delivery and research. This paperback costs \$20 and may be obtained by sending a check to AAMD; 1719 Kalorama Road, N.W.; Washington, D.C. 20009. Credit card orders may be placed by calling 1-800-424-3688.

**Use of Aversive Procedures with Persons Who Are Disabled: An Historical Review and Critical Analysis.**

Guess, D., Helmstetter, E., Turnbull, H.R. and Knowlton, S.; 1987. Monograph of The Association for Persons with Severe Handicaps (TASH). The authors are from the Department of Special Education, University of Kansas. The monograph covers a review and evaluation of aversive approaches to behavioral change, a demographic analysis of related published studies, issues that are legal, ethical and psychological both within and external to the field of disabilities and a discussion about the prevailing reticence with regard to use of punitive procedures for people with severe handicaps. Frank Laski, attorney with the Syracuse Public Policy Center, provides an epilogue on the legal challenges to aversive usage. The monograph may be ordered by sending a check for \$15 to TASH; 7010 Roosevelt Way N.E.; Seattle, WA 98115. This includes postage and handling costs.

**The Homecoming Model: Educating Students Who Present Intensive Educational Challenges Within Regular Education Environments.** This 70-page resource is a guide for establishing shared responsibility among teachers, administrators and parents for the education of students who present intensive educational challenges. It was published at the University of Vermont under the direction of Wayne L. Fox as part of a federal research and demonstration project funded by the U.S. Department of Education.

In the FOREWORD, Madeline C. Will, Assistant Secretary for the Office of Special Education and Rehabilitative Services endorses, as one approach, educational reform at the (school) building level. This model, the *Homecoming Project*, uses that approach.

Historically, students presenting intensive educational challenges to our public schools have been served outside of the regular classroom and, in many cases, outside of their local public school. This guide describes the *Homecoming* model that was developed through a federal demonstration project to assist teachers, related

service providers and administrators to educate all of their students within the least restrictive environment provided by the local public school. The model has enabled participating Vermont school districts to integrate students who present some of the most intensive educational challenges within regular classrooms.

As used here, the phrase "students who present intensive educational challenges" refers to those students who have been excluded from the regular classroom in their local school, or are "at risk" of being excluded. These students have been described for special education eligibility as mildly, moderately or severely retarded, multihandicapped, deaf-blind, autistic, behaviorally disordered or emotionally disturbed.

For the past three years, the staff of the *Homecoming Project*, along with the administration and instructional staff of 26 local schools, 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. The model includes transitioning students from early childhood/special education programs to local kindergartens upon reaching school age. This model has been adopted by, and is fully operational in four supervisory units across Vermont.

A total of 77 students, ranging in age from 5 to 17 years, benefited from the *Homecoming* model. Of these students, 58 have been transitioned from regional special educational programs to regular classrooms in their local schools. An additional 19 students who were at risk of being placed in self-contained special classes or out-of-district programs continue to be maintained within regular education environments of their local schools. Characteristics of the 58 students transitioned to local school regular classroom placements are varied. A large percentage (45%) of the total number of students were students with moderate or severe handicaps. To date, all of the 58 students who transitioned from regional programs to local schools have remained in their local school placements, avoiding re-referral to out-of-school placements.

The *Homecoming* model is based upon the concept of "shared ownership" among regular and special educators for the education of challenging students within regular classrooms in local public schools. The *Homecoming* model utilizes a building-based planning team and a consultative approach to deliver special education and related services to challenging students. The potential benefits of the *Homecoming* model are many. Students who present intensive educational challenges to their local schools will benefit from the collaborative planning of parents, regular and special educators, and administrators through increased opportunities for integrated educational and social experiences within regular education environments. Aside from the obvious benefits to all children of being

afforded the opportunity to attend their neighborhood schools, there are benefits to teachers, parents and administrators.

In the participating Vermont school districts, teacher collaborating to integrate students report that: (a) they have more say in what local educational programs look like; (b) they feel more comfortable asking for and receiving the material, technical and emotional support from colleagues to educate more challenging students; and, (c) the unique expertise of both regular and special educators in the building are more readily discovered and used. Parents report enhanced levels of participation in local school activities and in the planning of their children's education. Finally, administrators report more efficient use of resources; savings to the school district through the reduction of duplicated services; and increased understanding and support among administrators, regular class teachers, special educators, related services personnel, and families of one another's roles and needs.

In the chapters which follow, the *Homecoming* model is more fully delineated. The composition and potential functions of a local planning team are defined; steps which teams may follow in planning for local integrated education options are outlined; and methods for developing local educational resources and gaining access to specialized expertise are identified. A final chapter also has been added which identifies some of the major issues faced by administrators, special educators, teachers, and parents during model development and implementation in the participating schools. Copies of the *Homecoming Model* can be purchased for \$4.00 postpaid from MNASH; P.O. Box 1837, Pioneer Station; St. Paul, MN 55101. Allow three weeks for delivery.

## FEDERAL HIGHLIGHTS

The Subcommittee on Aging of the Senate's Labor and Human Resources Committee included in its amendments to the Older Americans Act (S.887), Title III, a provision that would include persons with disabilities as a target group. The amendments define persons with disabilities as those having functional impairments and a diagnosis of a medical condition which is included in a long list of medical conditions. State units and area agencies are to conduct joint planning activities with agencies serving people who are disabled. Title III provides funding for planning and coordination of services and also grants for direct services such as home-delivered meals, transportation, legal assistance and chore and homemaker help for people over 60.

# INFORMATION EXCHANGE

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SUPPLEMENT

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Association of  
Developmental Disabilities  
Councils

September 1987

## STUDY OF FRIENDSHIPS: WHAT IT'S LIKE TO BE "IN" BUT NOT "PART OF" A COMMUNITY

"Given the amount of resources and sheer human effort devoted to helping people with handicaps to reside in their communities, one might expect clients to live in much better circumstances in terms of their social interconnectedness. Yet, this cannot be judged to be the case. The lack of development in the area of human relationships for clients is astoundingly evident and disappointing. Community connectedness of clients has not kept pace with community placement of clients or the rapid expansion and local development of community residential services.

The above conclusions were stated in a study, *"Social Supports Research Project: Report of Findings,"* conducted by David I. Specht and Michael Nagy of the Western Massachusetts Training Consortium and the Holyoke/Chicopee Area Office of Mental Health, December 1986.

The overall purpose of the study was to investigate ways of studying the social relationships of formerly institutionalized persons with mental retardation and to provide information which could be used to help clients to establish social supports and become more socially integrated in communities where they live.

Social integration (that is, belonging to groups, having friends, and other social supports), according to a review of the literature, has been clearly linked to people's physical and emotional well-being. However, the development of social relationships has been especially challenging for persons who have been institutionalized and segregated from communities for extended periods of time, the authors observed. The authors suggested that the following findings could possibly point the directions for the next steps to be taken toward fuller social integration for clients:

1. Clients' relationships are typified by distorted patterns of relationships and by approximations of friendships with staff. For example:

- \* Relationships are almost exclusively with staff and care providers;
- \* Virtually all time and relationships are staff mediated or controlled;
- \* Few or no relationships exist with handicapped (including housemates) or nonhandicapped peers; and

- \* Clients have no best friend, few or no close friends, and few enduring relationships.

2. There is little consciousness or recognition of the importance of relationships for clients. For example:

- \* Only one program explicitly recognized the need or responsibility;
- \* There was no mention of relationship building in job descriptions; and
- \* The individual service plan is the primary (almost only) means of assessing needs, and it tends to be superficial and routinized, e.g., "socialization skills" are identified as the need.

3. There is little or no exploration of new relationships, maintenance of past relationships, or support of existing relationships. For example:

- \* Few clients had developed new, unpaid relationships and those that did were not likely to be intimate or close; and
- \* Since there is little relationship-building activity, it is not possible to speak to individualization and appropriateness of efforts.

4. The physical and social preconditions of programs for integration and building relationships are only partially met. For example:

- \* Nearly all programs failed to conceptualize and implement clients' need for a true home, despite good intentions.

5. Staff roles are unclear; staff lack knowledge, competencies, rootedness in community, and the commitment needed for relationship building. For example:

- \* Staff lack commitment to and knowledge of how to pursue relationships on behalf of clients.

While the picture painted by the study seemed bleak, the authors did not see the situation as being hopeless. Such hope existed where there was an awareness and a commitment to the clients' needs, where there were positive physical and social preconditions to facilitate relationships, and where increased training in the area of client social relationships could vastly heighten sensitivity to the issues.

Services that strived to authentically address clients'

relationship needs are most likely to have some of the following characteristics:

- \* There are highly positive values, beliefs, assumptions, and expectations about their clients, their acts of human service, and themselves;
- \* There is unity of ideology and clarity of service mission;
- \* There is a sense of mission unifying board, administration, staff, and clients;
- \* There is an identification with the clients;
- \* There is an intimate knowledge of, and commitment to, each client implying both smallness and a spirit of communality; and
- \* There are staff who are rooted in their clients' residential community.

Copies of the complete report may be obtained from: Western Massachusetts Training Consortium, Inc.; 187 High Street; Holyoke, Massachusetts 01040. Tel. (413) 536-2401.

### **A STORY THAT I HEARD**

This is the first article in a series during the coming months to share short stories of human interest. The following selection comes from the originators of the idea who recently published, **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 editors commented in the Introduction that:

"Our journals in the disability field give us many studies, statistics, and analyses, but few stories. Yet there is an important place, we think, for stories, for poetry, for reflective essays about the situation of people with disabilities in American communities."

Hopefully, readers of **Information Exchange** will appreciate other people's experiences of success, big and small, such as this month's selection:

#### **ATTITUDES**

by Betty Pendler

When my daughter Lisa, who has Down Syndrome, was very small and at the age when most parents take the children to the local playground, I knew it would be difficult since I would see other children her age performing at a far different level than hers. But I never expected to encounter the reaction of the parents.

This was a middle-class playground on the West Side of New York, and when I put Lisa in the sandbox, two parents rushed over and literally yanked their "darlings" out without even glancing at me. They were sure their children would "catch" Lisa's disease.

After repeated visits, this became too painful for me to handle, so I began going to another playground in a

lower socio-economic area, where there were many Puerto Rican families. What a contrast! I put Lisa in the sandbox, and a little Puerto Rican boy offered her his shovel. The mother came over to me, asked me in broken English what my daughter's name was, and gave me such a warm, open smile. Little did I know that a few years later, this little boy would be defending Lisa when she attended a summer program in the same area. When I came to pick her up at the summer program, I saw two young boys teasing her. This little boy from the playground rushed over and gave the two boys a strong lecture on how to be human beings.

Lisa and I made many friends at that playground, and this mother and her son keep in touch with us to this day--and that is over a span of 28 years!

### **TASH PASSES POSITION STATEMENT ON RELATED SERVICES**

On November 5, 1986, in San Francisco, the Executive Board of the Association for Persons with Severe Handicaps (TASH) passed several resolutions and position statements which can have nationwide impact upon the quality of services for persons with disabilities. This is the sixth and last in a series to share the TASH decisions in their entirety:

#### **Position Statement on Related Services**

The Association for Persons with Severe Handicaps is an international organization whose primary purpose is to advocate and support exemplary models of service delivery for persons with severe handicaps.

Many persons with severe handicaps have complex and challenging needs. The expertise of related services professionals such as physical therapists, occupational therapists, and speech and language pathologists is frequently required.

TASH believes that related services personnel have expertise and can contribute in the process of integrating persons with severe handicaps into typical home and community life. A high degree of collaboration and sharing of information and skills must occur among families, direct service providers, and related services personnel.

The provision of integrated services requires that related services personnel:

1. Establish priorities with parents/advocates and other team members;
2. Observe and assess persons with handicaps in natural settings;
3. Collaborate with family and team members to provide intervention strategies and adaptations that optimize participation in natural settings;
4. Teach specific and individualized procedures to enhance functional positioning, movement, and communication abilities in natural settings; and
5. Evaluate the effectiveness of intervention procedures

based on performance outcomes in natural settings. For more information, contact: TASH; 7010 Roosevelt Way, Northeast; Seattle, WA 98115. Tel (206) 523-8446.

### HOME OWNERSHIP ACCESSIBILITY LOAN PROGRAM

Assistance to first-time homebuyers with physical disabilities is available through the 1987 Single Family Home Loan Program of the Minnesota Housing Finance Agency (MHFA). Only homes that are accessible are eligible for financing under this special program. If buying an existing home that must be modified to make it accessible, the MHFA will lend additional funds up to 15% of the purchase price of the home to make accessibility improvements if the purchaser qualifies. For qualification requirements and other information, call: (612) 296-7613, or (800) 652-9747, toll free. Ask for "Home."

### PUBLICATIONS/RESOURCES

**Students in Transition Using Planning**, PACER Center, Inc., Minneapolis, 1987. This training manual consists of two components: 1) program for students, which outlines three classroom sessions for secondary age students with disabilities to help them build the skills needed to make the transition to life as adults; and 2) replicating the transition project, which assists others to present the program to secondary age students. Overhead transparencies designed to enhance the oral classroom presentations are also available for purchase. For more information, contact: PACER, Inc.; 4826 Chicago Avenue, South; Minneapolis, MN 55417. Tel. (612) 827-2966, voice or TDD.

**Achieving Outcomes: A Guide to Interagency Training in Transition and Supported Employment**, J. M. Everson, J. Barcus, S. Moon, M. V. Morton, Virginia Commonwealth University, May 1987. This manual is designed for staff trainers who provide interagency training to professionals and parents on community vocational training, transition planning, and supported competitive employment. Contents include in-service training, team building, training parents, employment-oriented vocational skills training, transition planning, and supported competitive employment training. Cost: \$13.95. Payable to: Virginia Commonwealth University; Rehabilitation Research and Training Center; VCU Box 2011; Richmond, VA 23284-0001. ATTN: Resource Dissemination.

**"Richard and Donna" Supported Employment Videotape** A new videotape, produced by the Department of Jobs and Training through the Minnesota Supported Employment Project, is part of an expanded marketing effort to interest employers in hiring workers with severe disabilities through supported employment. The 11-minute videotape entitled **"Richard and Donna: A Little Bit of Faith"** shows Richard Evans, who has mental retardation, a severe hearing loss, and cerebral palsy, and Donna Thompson, who has mental retardation, at work in a St. Paul Burger King restaurant. The title for the videotape is taken from a quote by Jay

Van Velzen, owner of the restaurant where Evans and Thompson work. "I guess it just takes a little bit of faith that people can do more than what you sometimes think they can." To borrow a copy of the videotape, call Ed Boeve, project director, at (612) 296-5629 or toll free at (800) 328-9095.

### CONFERENCES/WORKSHOPS

#### September 21-22, 1987

**Supported Employment: Department of Labor Standards, Payment Options, and Employer Incentives** is a technical assistance training program sponsored by the Minnesota Association of Rehabilitation Facilities (MARF) that will be held at the Sawmill Inn in Grand Rapids, Minnesota. For more information, contact: MARF Technical Assistance Program; 1821 University Avenue, Suite 376 South; St. Paul, MN 55104. Tel. (612) 646-0900, or MN WATS (800) 862-9090.

#### October 7, 1987

**Reconsidering Behavioral Approaches** is a special presentation by Herbert Lovett to be held from 3:30 p.m. to 5:00 p.m. at the Earle Brown Continuing Education Center, 1890 Buford Avenue on the St. Paul campus of the University of Minnesota. Herbert Lovett is the author of **Cognitive Counseling and Persons with Special Needs: Adapting Behavioral Approaches to the Social Context**. Cosponsors of this event are the Governor's Planning Council on Developmental Disabilities and the Minnesota Association for Persons with Severe Disabilities. Please register by calling (612) 296-4018. There is no charge for admission; however, attendance is limited to the first 80 people who register.

#### October 9-10, 1987

**A National Interdisciplinary Seminar on Down Syndrome** will be held at Quaker Square Hilton, Akron, Ohio. It will be presented by Blick Clinic, Inc., and jointly sponsored by Northeastern Ohio Universities College of Medicine, Summit-Portage Area Health Education Network, and Northeast Regional Training Consortium. For more information, contact: Blick Clinic, Inc.; 640 West Market Street; Akron, Ohio 44303-1465. Tel. (216) 762-5425.

#### October 15-18, 1987

**Rights Not Privileges: Strategies for Advocates** is a conference sponsored by the National Association for Rights Protection and Advocacy to be held at the Westin Hotel, Detroit, Michigan. Contact: NARPA Conference 1987; c/o Michigan Protection and Advocacy Service; 109 West Michigan Avenue, Suite 900; Lansing, MI 48933.

## 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.**

**A Handbook for Agency Self-Assessment: Volume I: Standards for Evaluating Administrative Practices of Human Service Organizations,** Health and Welfare Council of Central Maryland, 1980. This Handbook presents a list of standards relating to agency management in a format conducive to self-assessment of agency practice. Management areas covered are governance, financial management, personnel management, record keeping and statistics, legal obligations and reporting requirements, organizational planning, and community involvement and access to programs. The Handbook consists of generic standards of administration and indicators of adherence to the standards which are believed to have general applicability to the management of human service organizations. The standards are intended to assist agencies review their administrative practices and plan corrective actions and improvements which are needed.

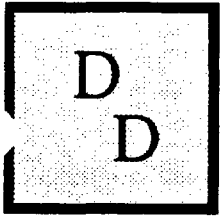
**Rehabilitation Technologies,** Research and Training Center, University of Wisconsin--Stout, 1986. This document provides information concerning resources, strategies, models, and techniques for making rehabilitation technology available to more persons with disabilities. Its main function is to help the rehabilitation practitioner understand and use technology along with other more traditional rehabilitation strategies to enhance the lives of persons with disabilities. Rehabilitation technology includes compensatory strategies and adaptive equipment to increase or improve functional capabilities of persons with disabilities. It is used to enhance the vocational, educational, and/or independent living opportunities for persons with disabilities. Resources for keeping practitioners informed about new developments are provided in the appendix.

**Metropolitan Council DD Program  
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St. Paul, MN 55101**

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# INFORMATION EXCHANGE



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## METROPOLITAN COUNCIL DD PROGRAM NEWS

### 1987: Quality and Integration

*"Family support is common sense. Family support is sound financial policy. Family support is reinforcing the family as the foundation of our society. Family support, in the best of systems, is the empowerment of families to choices and control over their destiny."*

So states Allan I. Bergman in the first issue of **"Family Support Bulletin"** published by United Cerebral Palsy Associations, Inc. Mr. Bergman notes that,

*"It is a sad commentary on our society that until the late 1970's, the bulk of our local, state and federal legislation provided funding for children with special needs to live outside of the family home. In spite of the advances made in many states, nearly one-half of the states today still offer minimal or no financial or service support to families. Financial policy has become, in many ways, a perverse incentive to break up families."*

The **"Family Support Bulletin"** is a free quarterly that will disseminate information on research, policy and exemplary practices and financing related to supporting families (natural, adoptive and foster) to rear their children who have severe disabilities or chronic illnesses in their own homes. The bulletin will also feature news about a national network of families, friends, providers, government agency officials and elected policy makers who are committed to consistent policies that support families.

This information activity and UCPA's role is one part of a three-year project to be carried out by Human Services Research Institute (HSRI) in Cambridge, Massachusetts. The project was funded by a grant from the National Institute on Disability and Rehabilitation Research of the U.S. Department of Education. The goal

of the project is to identify quality models that support and sustain family care for these children. The project will include a survey of families to identify elements that are critical in assessing the financial costs of providing home care. This information will be supplemented with a review of literature in the field, intensive case studies of families raising their children at home and opinions of health care experts concerning the costs associated with providing home care for children with a variety of chronic illnesses and severe disabilities.

During the second phase of the project, states will be asked to submit proposals for the development of demonstration projects using new models for financing and supporting home care. The selection of demonstration sites will be based upon the following criteria: the involvement of key public and private sector agencies; the overall impact of the project on the well-being of families; the probability of success and subsequent acceptance of the model; and the level of commitment of the sponsoring agency.

The project will also include several national symposia that will introduce participants to alternative financing models and provide an opportunity for the project's network of organization representatives and others to participate in the critical review of issues and policies affecting the capacities of families to provide care and support in their own homes.

For additional information about this project contact: Allan I. Bergman, Deputy Director of Governmental Activities, United Cerebral Palsy Associations, 1522 "K" Street, N.W., Washington, D.C. 20005, (202/842-1266), or Valerie Bradley, President, Human Services Research Institute, 2336 Massachusetts Avenue, Cambridge, Massachusetts 02140, (617/876-0426).

To be put on the mailing list for **"Family Support Bulletin,"** write to UCPA at the above address.

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.

## AND SPEAKING OF FAMILIES

The following item is reproduced with permission of the PACER Center:

### The Twelve Commandments for Parents of Children with Disabilities

- I. Thou art thy child's best and most consistent advocate
- II. Thou has valuable information about your child. Professionals need your input.
- III. Thou shalt put it in writing and keep a copy.
- IV. Thou shalt try to resolve problems at the lowest level but not hesitate to contact a higher authority if problem not resolved.
- V. Thou shalt keep records.
- VI. Thou shalt seek out information when needed.
- VII. Thou shalt take time to think through information before making a decision.
- VIII. Thou shalt have permission to be less than perfect. Important lessons are learned from both successes and failures.
- IX. Thou shalt not become a martyr. Decide to take a break now and then.
- X. Thou shalt maintain a sense of humor. It is great for your emotional well being and that of your child.
- XI. Thou shalt always remember to tell people when they are doing a good job.
- XII. Thou shalt encourage thy child to make decisions because one day he or she will need to do so.

by Virginia Richardson  
PACER Parent Training Coordinator

### HSRI On Family Home Care

One of the first products of the federal grant mentioned above is now available. The **Annotated Bibliography On Family Home Care** includes current articles and books as well as published manuscripts addressing various issues surrounding family home care for children with chronic health needs and severe disabilities. The bibliography can be purchased from HSRI for \$10.00 to cover the cost of duplication and postage. Orders with a check should be sent to HSRI; 2336 Massachusetts Ave.; Cambridge, MA 02140.

### MAHI HAS NEW PARENT GROUP

The Metropolitan Association for Hearing Impaired (MAHI) announces formation of a new parent support group. Monthly meetings will be held on the first Thursday of each month at the Catholic Deaf Church in northeast Minneapolis. Attendance is free and arrangements for free child care are planned. Meetings will include either a presentation on a specific topic or discussion on topics suggested by those present at the meeting. For meeting time and more information: Maureen Kramlinger, (612) 827-1324 (V) or Carolyn

Anderson (612) 521-8416 (V/TDD).

### \$716,000 TO TAPS

The Epilepsy Foundation of America has received \$716,000 from the Department of Labor to fund the Foundation's employment program for people with epilepsy. The funding, an increase of \$21,000 over last year, will enable the Foundation to continue operating its highly regarded Training and Placement Service (TAPS) in 13 cities and expand it to a 14th site.

An additional four TAPS programs are funded separately through the Tony Coelho Jobs Fund. From its beginning in August, 1976, as a placement project for 600 people in five cities, TAPS has grown to become a major national program. It has achieved a respected status among employment programs serving persons with handicaps, consistently demonstrating one of the highest placement rates (76 percent) of any such program. Over the years TAPS has served over 11,000 people with epilepsy and placed over 9,000 in jobs.

### ISSUE PAPERS AVAILABLE

The Minnesota State Council on Disability has prepared issue papers that are available to the public free of charge. Listed below are those papers' titles. To secure a copy, send a stamped, self-addressed envelope to: MSCD; 208 Metro Square Building; St. Paul, MN 55101.

- Access '92: An Update on the Council's Major Accessibility Program
- The Federal Tax Reform Act of 1986 - Its Effects on Persons with Disabilities
- Major Disability Rights Victory: School Board of Nassau County v. Gene H. Arline
- A Review of the 1987 Legislative Session: Disability Related Legislation
- A Review of the 99th Congress Disability-Related Legislation
- Welsch vs. Gardebring: Moving Toward Resolution
- Minnesota's New Handicapped Parking Law.

### REQUESTS FOR ASSISTANCE

#### Successful Accessibility Solutions?

Barrier Free Environments, Inc., of Raleigh, North Carolina, needs creative solutions people have used to make their homes accessible. They may be for the entire home, part of the home, such as the kitchen, bathroom or entrance, or for a detail such as a window or switch. The information is being collected as part c



a three-year research and demonstration project on accessible housing sponsored by the National Institute on Disability and Rehabilitation Research. The project, entitled **"Less Restrictive Housing Environments: Examples, Methods, Designs, and Guidelines for Improving New and Existing Housing"** will develop improved design guidelines and solutions for accessible housing.

The ideas may be included in training materials used by individuals with disabilities, designers, architects, and members of the housing community. Please send written descriptions, photographs, drawings and videotapes, if available, to: Less Restrictive Housing Barrier Free Environments, Inc.; P.O. Box 30634; Raleigh, N.C. 27622; (919)782-7823).

## RESOURCES/SERVICES

### Independence Crossroads Support Groups

Independence Crossroads currently sponsors seven support groups for people with disabilities in the Metro Area. The direction of each group is based on the particular needs of its members. All of the groups provide an atmosphere where sharing and support is encouraged. Many times friendships develop as a result of the group's interactions. Some of the groups are made up of people with the same disabilities, others are for people with differing disabilities, for women, for mothers and for teenagers. For more information, write or call Independence Crossroads; Room 422; 4240 Fourth Avenue South; Minneapolis, MN 55409; (612) 822-5655.

### Accessible Tennis Courts

The City of Bloomington has two accessible tennis courts available for use by individuals with a physical disability. A key is needed for accessible entrance to the courts and may be obtained by calling Bloomington Parks & Recreation at 887-9601, ext. 231 or TDD: 887-9677. The courts are located at Brookside Park (2 courts) 102nd and Xerxes Avenue South and Valley View Park (6 courts - lighted) 90th Street and 3rd Avenue South.

### University Composition Course

Adults with hearing impairments will again have available a composition course offered by the University of Minnesota for the Fall and Winter Quarters, 1987. For more information call Deb Guthman, (612) 624-4037 (V/TDD).

## Attendant Services Network

Expanding the availability of attendant services in the United States is a priority of the World Institute on Disability (WID). Toward this goal, WID has launched its new publication, **Attendant Services Network**. The publication will be a vehicle for sharing information about attendant services among people with disabilities, advocates, planners, and policy makers.

The first issue focused on the highlights of WID's survey of publicly funded attendant services in the U.S. The survey's report, loaded with statistics and findings, notes that there is no comprehensive system of attendant services anywhere in the U.S. With only a small number of references to attendant services embedded in the policies established by the U.S. Congress such as Medicaid and the Older Americans Act, states have recognized the need but have tended to develop their own programs with little communication with other states. Too many of the programs still foster dependency for individuals with disabilities. Future issues of the newsletter plan to address attendant training and management, paramedical and liability issues. To subscribe to the newsletter or for copies of the report, **"Attending to America,"** write: Its World Institute on Disability; 1720 Oregon Street, Suite 4; Berkeley, CA 94703; (415)486-8314).

## FOR YOUR INFORMATION

### PACER '87 Fall Workshops

Parents of children and youth with handicaps are invited to PACER Center workshops in the Twin Cities Area. PACER is a statewide coalition of 17 Minnesota disability organizations. It offers information to parents that can help them learn about, better understand and use the complicated service systems that provide services to their children. To receive a brochure listing the fall workshops, write or call: PACER; 4826 Chicago Avenue South; Minneapolis, MN 55417-1055; (612) 827-2966 (V/TDD).

### MINN-DACA Conference

The Minnesota Developmental Achievement Center Association will sponsor a conference, **"Focus on Quality."** The conference will highlight sessions on governmental affairs and staff training. The conference will take place at Madden's Inn in Brainerd, Minnesota on October 15 and 16, 1987. To receive more information on conference registration and accomodation costs, write or call: MINN-DACA; 1821 University Avenue, S-277; St. Paul, MN 55104; (612) 647-9200.

## Family Lecture Series

A fall information series for families, professionals and others will be presented by the Association for Retarded Citizens of Hennepin County. The sessions include information about county services, estate planning, policy and law-making, "letting go" to better ensure growth and development. A flyer listing the sessions, schedule and fees is available. Call or write: ARC of Hennepin County; 2344 Nicollet Avenue South, Room 370; Minneapolis, MN 55404; (612) 874-6650.

## Leisure Connections

Leisure Connections is sponsored by the ARC of Hennepin County. It enables people with developmental disability to be involved in community social and recreation programs with a volunteer companion. Persons with and without a disability are matched for participation together in time-limited leisure programs conducted at community sites. For example, participants might choose to take an aerobics class at a local "Y", an art class through community education, or a gardening class at an area nature center.

Program participants are matched with regard to gender, age, interests, residence proximity and time available. If you are interested in exploring a new way to make a friend and have fun in the process, Leisure Connections is for you. For more information, please call Nancy Thysell at (612) 874-6650.

## Nonprofit Directory Planned for Fall

The Minnesota Council of Nonprofits will be publishing the **Minnesota Nonprofit Directory** in Fall 1987. The Directory will feature profiles of 1200 Minnesota nonprofit organizations. An organization's listing in the directory is free, upon receipt of a completed survey. Any state organization interested in being listed in the Minnesota Nonprofit Directory should call or write the Minnesota Council of Nonprofits for a survey form. MCN; 2700 University Ave. W., #250; St. Paul, MN 55114; (612) 642-1904.

## United Arts Sets Workshop Dates

United Arts announces its fall schedule of workshops with sessions geared to nonprofit organizations. Included are sessions ranging from grant writing and time management to new laws for nonprofits and stress management. Prices range from free to \$85 for a series of six programs. Some sessions are evening programs, others are all-day events. A brochure describing the fall schedule is available by writing Resources and Counseling; United Arts; Landmark Center; 75 West 5th St.; St. Paul, MN 55102; (612) 292-4381.

## Library Materials and Services

Hennepin County libraries offer extensive informational materials and services to persons with hearing or visual impairments. They have TDDs, large print books and talking books. Other libraries in the state provide similar services. Reference service and free request/reserves for books are available by using TDDs (830-4927 and 566-2233).

## 1987 Legislative Roundtable

The Minnesota State Council on Disability will host its 1987 Legislative Roundtable on November 18, 1987 from 1-4 p.m. at the Holiday Inn Capitol in St. Paul, Minnesota. For more information call Wendy Brower, (612) 296-2029 or toll free 1-800-652-9747 (V/TDD).

## Community Education South Hennepin County

Fall, 1987 programs for South Hennepin County residents who are handicapped provides one of the most varied array of programs in the Metro Area. If you live in this area and wish to receive a copy of the schedule, write or call: The Learning Exchange, 8900 Portland Avenue South; Bloomington, MN 55420; (612) 887-9226 or 887-9144 (TDD).

## Special Education Workshops

The Association for Retarded Citizens Suburban will present a series of special education workshops to be held in local school districts in East Metro counties. It is open to parents, educators, therapists, school board members and others. Dorothy Skarnulis will present information on the importance of integration of students with handicaps with their non-disabled peers. She will also give examples of how state-of-the-art principles can be put into practice. Ms. Skarnulis is the parent of an 18 year old son with multiple needs. She is on the staff of the University Affiliated Program on Developmental Disabilities, a licensed school social worker and chairperson of the DD Advisory Committee of the Metropolitan Council. For more information: ARC Suburban; 14451 County Road 11; Burnsville, MN 55337; (612) 431-3700.

## A Special Concert

The Friends of Gillette, the auxiliary of Gillette Children's Hospital, will present a Special Concert at 8 p.m., Thursday, October 29 at the Ordway Music Theatre in St. Paul. The benefit features the Saint Paul Orchestra and guest artist Pinchas Zukerman, performing works by Beethoven, Barber, and Vivaldi. Ticket sales will be donated to Gillette's Free Care Fund. The fund helps families who cannot afford medical care for their disabled children. Tickets are \$250, \$100, \$50, \$25, and \$17.50 and are available from the Ordway Box Office. Gillette Children's Hospital is a regional health center.

for young people with disabilities.

### **RFP: Job Programs For Older Workers**

The State Job Training Office (SJTO), an office within the Minnesota Department of Jobs and Training (MDJT), is requesting proposals from appropriate organizations and units of government to provide employment and training services to older workers. The program, authorized by Section 124 of the Job Training Partnership Act (JTPA), is designed to provide for the training and placement of low income persons 55 years of age and older in employment opportunities with private business concerns.

A minimum of \$300,000 is available to fund programs to operate between January 1, 1988 and December 31, 1988. To obtain a copy of the application package or for more information, contact: Jim Korkki, SJTO, MDJT; 690 American Center Building; 150 E. Kellogg; St. Paul, MN 55101; (612) 296-6061. Proposals must be received by 4:30 p.m., Friday, November 6, 1987.

### **District and Local Coordinators Meeting**

Very Special Arts-MN, an educational affiliate of the John F. Kennedy Center for Performing Arts will hold a district and local coordinators meeting to discuss development of statewide Very Special Arts satellites. VSA-MN works to bring quality arts programs to people of all ages who are disabled. If you are interested in helping to set up a satellite in your area, please contact: Susan Harden, Executive Director, at (612) 922-2928 or write to: Very Special Arts; 5701 Normandale Rd; Edina, MN 55424.

### **CONFERENCES/WORKSHOPS**

#### **October 29-31, 1987**

The Association for Persons with Severe Handicaps (TASH) will hold its 14th Annual Conference at the McCormick Center Hotel in Chicago, Illinois. The theme of the meeting is **"Back to the Future: Integration Revisited."** Workshops, panel presentations, and papers will be offered on community and school integration issues including residential, vocational, educational and social/sexual development; infant and family issues; legal issues; nonaversive intervention techniques; self-advocacy; technology and related services. Note that registration for parents of persons with severe handicaps is free. Conference packets may be requested from TASH; 7010 Roosevelt Way, Northeast; Seattle, WA 98115. Tel (206) 523-8446.

#### **October 30-November 1, 1987**

Epilepsy Foundation of America National Conference will be held at the Sonesta Beach Hotel in Key Biscayne, Florida. For registration forms or other information: Diane Lipsey, Conference Coordinator; EFA; 4351 Garden City Drive; Landover, MD 20785; (301) 459-3700.

#### **December 7 and 8, 1987**

**"Non-Aversive Behavior Modification"** is the title of a two day professional training seminar sponsored by REM, Inc. and ARRM at the Thunderbird Hotel in Bloomington, Minnesota. Gary W. LaVigna, Ph.D. and Thomas J. Willis, Ph.D., directors at the Institute for Applied Behavior Analysis in Los Angeles, California will be the faculty for the seminar. For more information: David Pfriem, 6921 York Avenue South; Edina, MN 55435; (612) 925-5067; toll-free in Minnesota: 1-800-682-3824; outside Minnesota: 1-800-245-3860.

### **PUBLICATIONS**

**Getting Employed, Staying Employed - Job Development and Training for Persons with Severe Handicaps.** C.S. Mccloughlin, J.B. Garner and Michael Callahan (Eds.) Paul H. Brookes Publishing Company, 1987. Cost: \$22.95. This practical book provides detailed suggestions for the major steps in obtaining and maintaining employment for persons with developmental disabilities. It assists service providers with guidelines and detailed procedures for resolving many of the issues that arise in supported employment: securing quality employment, negotiating successfully with employers, dealing with problem behavior on the job, and fading back support.

One section of the book outlines each stage of the process, identifies problems in the various stages and suggests strategies for overcoming them. Another section helps the reader learn how to provide better on-the-job training and support and how to increase the employee's productivity. The Foreword by Bob Perske gives an excellent history of Marc Gold who pioneered employment for persons with severe handicaps. The editors are people who worked with him as he developed and refined "Try Another Way."

The book can be ordered by calling toll-free: 1-800-638-3775. It is available from the Curriculum Library of the DD Program, Metropolitan Council. It cannot be circulated outside the Twin Cities Metropolitan Area.

## Autism Information

Two publications, one new and the other in its twenty-first year provide information about autism:

- **Communication**, the journal of The National Autistic Society, 276 Willesden Lane, London NW2 WK; Simon Baron-Cohen, Editor; and

- **Autism Research Review**, published for the first time this year by the Institute for Child Behavior Research, 4182 Adams Ave., San Diego, CA 92116; Bernard Rimland, Ph.D., Institute Director and Review Editor.

**Communication** has appeared in several formats over the years. Currently it is an attractive magazine (20 plus pages) featuring articles by both parents and professionals, poems (often by persons with autism), art work by autistic persons, news from Great Britain, Europe, Canada and the United States; book reviews, reviews of scientific research, editorials, commentary on a variety of issues (occasionally including controversial matters), and letters to the editor. Inquiries about subscriptions can be made to the editor at the above address.

**Autism Research Review** (ARR), a quarterly publication edited by Bernard Rimland, founder of the National Society for Autistic Children (now the Autism Society of America), is designed to review medical and educational research in the field of autism and related disorders.

The first issue (8 pages) is crammed with brief items on numerous subjects including autopsy studies, magnetic resonance imaging (MRI) studies of the brains of persons with autism, early intervention, savant skills, impramine studies, viral infection studies, Fragile X Syndrome studies, research in behavior management (including a brief report on CSAAC's Marcia Smith's work with positive reinforcement at job sites), use of sensory reinforcers, etc.

The 1987 issues of ARR are published under a grant. Subscriptions for 1988 are \$15 (U.S.) and \$17 (outside U.S.). Inquire by writing to AAR at the above address.

## FEDERAL HIGHLIGHTS

### SSI Work Incentive Rules Permanent

Recent legislation modifies and makes permanent work incentive provisions under Section 1619 of the Social Security Act which were due to expire on June 30. Section 1619(a) allows disabled recipients who work to keep receiving cash benefits until their earnings reduce their SSI payments to zero. Section 1619(b) continues Medicaid protection for disabled people whose earnings are too high for SSI payments, as long as they remain medically impaired, need Medicaid in order to work,

and cannot afford to replace the Medicaid benefits. SSI recipients can be eligible for Section 1619 benefits in any month after the first month they join the SSI rolls.

The new provisions require all states to continue Medicaid coverage to those who were receiving it in the month before qualifying for Section 1619 benefits. This coverage was not available in all states before. Under the old law, recipients who had been receiving Section 1619 benefits often had to reapply for regular SSI benefits if their work attempts failed. Recognizing that severely impaired recipients who make work attempts may not be able to show steady improvement, the new provisions allow relatively free movement between regular SSI benefits and 1619 eligibility. Even people who have worked their way off the SSI rolls can go back to cash benefits and/or Medicaid if their income drops to eligibility levels within 12 consecutive months.

The new legislation is based on the demonstrated potential of the work incentive rules for helping recipients return to work and leave the payment rolls. About 55,000 people have participated in the program since it started in 1981 as a demonstration project. A significant number began working or increased their earnings only because they knew they would continue to receive Medicaid and would also receive SSI if their work effort failed. For more information about these rules contact a local Social Security office.

### NRICH Training Update

The National Resource Institute for Children and Youth with Handicaps (NRICH) recently provided a three-day training session for Washington State child welfare workers from the Department of Health and Human Services and staff of the Division of Developmental Disabilities.

The training covered genetics, diagnosis and medical consideration for DD, values clarification, child development, and social work practice. The joint session provided participants with opportunities to gain insight into the workings of each other's department and to encourage relationships that will carry over into the service field.

Portions of the training can also be presented in other states and at selected conferences. NRICH training and resources are available to practicing professionals working with children who are developmentally disabled and who are receiving or in need of child welfare services. For information, contact NRICH; University of Washington; Mall Stop WJ-10; Seattle, WA 98195; (206) 543-2254.

# INFORMATION EXCHANGE

STATE  
SUPPLEMENT

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

October 1987

## B. F. SKINNER SPEAKS OUT ON AVERSIVE TREATMENT

In an article written by Daniel Goleman appearing in **The New York Times** (August 16, 1987), Burrhus Frederic Skinner, the chief architect of behaviorism, is preparing a crusade against what he sees as grave mistakes in psychology that have left his own once preeminent theories in decline. Behaviorism holds that people act as they do because of the rewards and punishments--positive and negative reinforcements--they have received.

The use of punishment is one of several issues about which Skinner still feels impassioned. He is an ardent opponent of the use of punishment such as spanking, or using "aversives" such as pinches and shocks with children who have autism.

"What's wrong with punishments is that they work immediately, but give no long-term results," Skinner said. "The responses to punishment are either the urge to escape, to counterattack, or a stubborn apathy. These are the bad effects you get in prisons or schools, or wherever punishments are used."

Skinner expanded upon the above statements in another interview held recently by Marcia D. Smith, Consulting Psychologist with the Community Services for Autistic Adults and Children, Inc., in Rockville, Maryland (an article appearing in **Community News**, Summer 1987). With regard to the effectiveness of punishment, Skinner observed that it will change behavior. "Punishment works immediately--if you are powerful enough. For example, if someone does something you don't like, strike him and he will stop," Skinner smiled. "However," he continued, "every person who is punished will get away if he can. As a side effect of punishment, there are counter-attacks on people and . . . a stubborn, do-nothing, sullen response. Other responses include withdrawal, anger, retreat, avoiding personal contact and so on. This is very bad. It has taken us a long time to discover something better."

Smith observed that these responses are characteristics of people with autism who have been punished and she asked, "Is it possible that these are side effects of punishment?"

"They certainly are that," replied Skinner. He then added, "As an alternative to punishment people should attempt to create environments in which persons with behavior difficulties are reinforced naturally for behaviors which are good for society. To do so will require significant change," he observed, "since punishment has been used throughout history, and we have learned that it feels better to be well-behaved after punishment than

to be well-behaved because there was no inclination to do otherwise. The problem is to find ways to build a world in which the behaviors you want are positively reinforced and the behaviors you don't want are not. It is better than punishment."

"So, it is the goal, then, to fill lives with positive reinforcements?" asked Smith. "Yes," replied Skinner. "Only a full understanding of the continuous use of positive reinforcements can show how powerful it really is."

Note from the Editor: At the time of his interview with **The New York Times**, Skinner was preparing his presentation to the annual conference of the American Psychological Association, and an article that will be published in the **American Psychologist** in September. At age 83, Dr. Skinner is still vigorous in arguing his cause. The interview conducted by Smith was videotaped and may be purchased for approximately \$25.00. For more information, contact: Community Services for Autistic Adults and Children, Inc., 751 Twinbrook Parkway, Rockville, MD 20851. Tel. (301) 762-1650.

## FEDERAL COURT ISSUES PLAN AND ORDER OF DEINSTITUTIONALIZATION IN OKLAHOMA

On July 24, 1987, U.S. District Judge James Ellison in Oklahoma filed a Court Plan and Order of Deinstitutionalization: Introduction, Values, and Guiding Principles regarding all persons who at the time of the complaint (August 1, 1986) were at the Hissom Memorial Center, Sand Springs, Oklahoma, and all persons who become clients of Hissom during the time of this action. Following are highlights regarding Homeward Bound vs. Hissom Memorial Center class action suit.

According to a memorandum dated July 25, 1987, from Frank Laski, Timothy Cook, and Judith Gran from the Public Interest Law Center of Philadelphia, and Louis and Patricia Bullock of Bullock and Bullock (who represented the Plaintiffs), "The Court's decision is an unqualified victory for the plaintiff class and for Homeward Bound--Association for Retarded Citizens, the organization of Hissom Memorial Center parents that brought the action." Judge Ellison found that conditions at Hissom violated fundamental statutory and constitutional rights of the plaintiffs, and ordered defendants to implement as a remedy a comprehensive plan to serve class members in the community.

The Order provides that all 450 current residents of Hissom will be placed in the community over a four-year period, beginning with 75 persons in the first year and 125 per year thereafter. During each year, persons with all levels of need (including those with

multiple handicaps, serious medical needs, and challenging behavior) will be placed with appropriate services and supports. Admissions to Hissom and capital construction at the institution will cease. Defendants are to identify all class members not presently at Hissom and to develop a plan to serve those individuals. This latter group (estimated at about 1,500 persons) includes former Hissom residents now living in nursing homes and large private institutions, and former residents living at home without services.

The following guiding principles were established in the introduction of the Judge's Order to direct the remedy developed by the parties as they create community alternatives for persons with mental retardation in Oklahoma:

- All persons are capable of growth and development.
- All persons deserve to be treated with dignity.
- All persons have value.
- All persons must be involved in and carry the primary responsibility for the decisions which affect their lives.
- All persons should live and work in the most natural settings.
- All children should live with families.
- All children have the right to a free and appropriate education.
- All persons should live in and be a part of the community.
- All citizens have the right to fully exercise their rights as guaranteed by the Constitution of the United States.

Judge Ellison's findings of fact on conditions at Hissom included: regression; deterioration; denial of adequate food; clothing and medical care; lack of necessary habilitative programs and therapies; dangerous feeding practices; lack of adequate sanitation; frequent injury and abuse; and the pervasive harm of segregation.

The Court also found violations of Section 504 of the Rehabilitation Act in defendants' failure to provide services to class members except in segregated settings, and their discriminatory denial of habilitative services to class members with severe handicaps. The Court made factual findings that the state of Oklahoma had intentionally segregated people with mental retardation in institutions for the welfare of the community because of prejudice and stereotype, and that the state had actively encouraged communities to send their citizens with mental retardation to state institutions.

Although the Hissom case parallels the findings of all other federal courts that have ruled upon the conditions imposed upon persons with mental retardation residing in large, isolated institutions, this Court's opinion and Order are remarkable in several respects, as stated in the Laski et al., memorandum. The result is an order based solidly in the values, knowledge, and technology of the 1980s in providing effective services to persons with mental retardation. The plan includes:

- Family care, specialized foster care, and supervised homes and apartments as the preferred residential service models, with the traditional small group home considered a backup for class members for whom a better option cannot be developed;
- Individual program planning defined as the

development of services to an individual in his home rather than placement into a facility, slot, or bed, with class members living wherever possible in homes they purchase or rent themselves;

- Employment services as the preferred day program model, including vocational program models of proven effectiveness in serving persons with severe handicaps;
- Independent case management and case manager to client ratios of 1:10;
- A comprehensive system of monitoring and safeguards involving families, consumers, self-advocacy organizations and ordinary citizens.

No class member will be placed in a home with more than six residents. The great majority of class members will live in homes with three or fewer residents with mental retardation.

Initially, a Court representative will be appointed to assist the Court in reviewing reports on the defendants' implementation. In the event that this proves insufficient to assure compliance with the Court's Order, more detailed monitoring will be required including review of specific interdisciplinary team assessments against placements to assure that class members' needs are being met. Should that level of monitoring in turn prove insufficient, the Court would in effect place defendants' programs for class members in receivership. The Order became effective in September 1987.

The Court concluded that all Hissom residents must be placed in the community. This conclusion was based squarely on the evidence presented at trial rather than abstract concepts of the least restrictive alternative. During six weeks of trial, defendants were unable to show that any class member benefited from being at Hissom rather than in the community. The Court noted the holding of the Court of Appeals for the Third Circuit in **Halderman v. Pennhurst** in 1979 that resort to institutionalization might be permissible for some persons. Nevertheless, the Homeward Bound Court concluded that the evidence before it in this case could not support or justify resort to the institution for any member of the class. Judge Ellison concluded, "This trial Court, sitting in Oklahoma in 1987, upon consideration of the overwhelming evidence . . . must conclude that constitutional, federal, and statutory requirements now dictate removal of the institution as a choice of living environment for such individuals."

A packet of documents (including the, memorandum from Laski et al., Findings of Fact and Conclusions of Law, Court Plan and Order of Deinstitutionalization: Introduction, Values, and Guiding Principles; and a series of articles from **The Tulsa Tribune**) are available upon request from: Minnesota Governor's Planning Council on Developmental Disabilities, 300 Centennial Office Building, 658 Cedar Street, St. Paul, MN 55155. Tel. (612) 296-4018.

#### **STATE PLANNING AGENCY/DEVELOPMENTAL DISABILITIES MOVES TO NEW ADDRESS**

On September 23, 1987, the Minnesota Governor's Planning Council on Developmental Disabilities office and the entire State Planning Agency moved to the following address: 300 Centennial Office Building, 658

Cedar Street, St. Paul, Minnesota 55155. Telephone numbers will remain the same: (612) 296-4018, or (612) 296-9962 (voice or TDD).

### **SUMMARY OF ADVISORY TASK FORCE MEETING--JULY 3, 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 bi-monthly and acts upon those issues presented by various work groups and departmental staff members. Following is a summary of their meeting held on July 13, 1987:

- Duane Shimpach, Chair, suggested that a singular model of providing case management services be adopted by the counties.

- The Work Group on Case Management, as reported by Dick Cohen, has reviewed existing literature and find that many of the basic components for a good case management system are already in place or are under development: 1) clear and enforced standards; 2) implementation on a local level; 3) case managers employed by entities who are not responsible for service provision. The primary weaknesses of case management are: 1) knowledge and values are important preservice and in-service training, adequate supervision, and support are necessary; 2) manageable caseloads; 3) external monitoring system for case management; 4) adequate funding; and 5) the system cannot have gaps in services.

- Shirley Schue of the Division for Persons with Developmental Disabilities of DHS summarized some of the activities taking place throughout the state regarding case management: 1) the University Affiliated Program at the University of Minnesota has conducted a survey on case management and will be cosponsoring a conference on September 21 and 22, 1987; 2) the Governor's Planning Council on Developmental Disabilities has awarded a second-year of grants in the area of case management of which some of them are to the Association for Retarded Citizens/Suburban on parent case management, Dakota and Itasca Counties on the reduction of paperwork (via the use of portable personal computers), the Metropolitan Council to assemble a best practices manual for counties; 3) a new service evaluator position has been added to the staff of the Division for Persons with Developmental Disabilities; and 4) case management training has been scheduled at 16 or 17 sites around the state this fall and winter.

- Anne Henry reported that the work group on external monitoring will have a first-draft report in September.

- The Work Group on Training, led by Lee Slagter, has conducted a survey which thus far has identified two barriers to the provision of personnel training--lack of money and the high rate of turnover.

- Tom Fields distributed the Commissioner's newly proposed organizational chart for DHS.

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, 444 Lafayette Road, St. Paul, MN 55155. (Note: this is their new address.) Tel. (612) 296-2147.

### **A STORY THAT I HEARD**

The following selection of short stories 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:

#### **YELLOW PAD STORY**

By Betty Pendler\*

When Lisa and her brother were very small I was seeking day care services. I finally found a local community group that was willing to accept Lisa in their summer program, and she did very well, and it was a very successful and exciting experience. Therefore, I had the courage to approach the city Day Care Nursery. Fortunately, the director of this nursery was acquainted with the director of the community center which had accepted Lisa for the summer, so she was quite amenable to the idea. However, she cautioned me that Lisa had to be cleared by a social worker from the Department of Social Services.

I approached the playground of the Day Care Nursery with much excitement and saw a social worker seated with a yellow pad on her lap. I know now, but did not know then, that people who don't talk well have a tendency to touch. Lisa had very little speech at that time. She approached and touched a young child, and I noted that the social worker immediately wrote something on her yellow pad. Lisa, being quite a sociable little girl, went over to another child and touched her, and once more the social worker wrote something on her yellow pad.

When we entered the director's office, this social worker indicated that Lisa exhibited aggressive behavior, and she had some concern about what the mothers would say. My sole comfort was that I knew the director was amenable to accepting Lisa, so it was she who suggested that Lisa attend on a trial basis. Needless-to-say, she did very well and remained there until she entered public school.

But here is the point of the story. The following year her brother, Paul, reached age 3, so I brought him to the Day Care Nursery. Once again, there was a social worker, a different one, but she, too, had a yellow pad on her lap. Paul, who is a healthy, normal, chubby boy, spied the jungle gym, and rushed toward it, pushing a little boy on his way . . . and nothing was written down on that yellow pad.

\*Betty Pendler lives in New York City, is retired, and spends her time with advocacy issues; in particular, sensitizing professionals to the parents' perspective. She serves on the New York Developmental Disabilities Council, and on the Advisory Board of **Exceptional Parent** magazine. Lisa has Down Syndrome, and now lives in a community residence in New York City. Paul is now a graduate student at the University of Missouri in Psychology and Counseling.

## 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.**

**The Maine Approach: A Treatment Model for the Intellectually Limited Substance Abuser**, Maine Department of Mental Health and Mental Retardation and Kennebec Valley Regional Health Agency, 1984. This book serves as a guide to human service professionals to address problems of substance abuse by clients with intellectual functioning. The problem of dealing with alcohol and substance abuse by citizens with mental retardation is compounded by limited resources to serve this population as well as the realization that expertise in alcohol/substance abuse and expertise in mental retardation programs are seldom found in the same professional. In addition, conflict in treatment philosophies make it difficult to have consistent and coordinated efforts among various agencies serving substance abusers with limited intellectual functioning. Guidelines and resources are provided to assure that existing programs can be adapted to client needs, rather than how clients can adapt to programs.

**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.

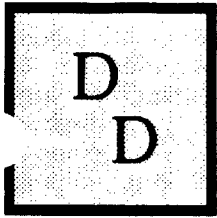
**Metropolitan Council DD Program  
300 Metro Square Building  
7th and Robert Streets  
St. Paul, MN 55101**

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# INFORMATION EXCHANGE



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## METROPOLITAN COUNCIL DD PROGRAM NEWS

### Introducing FY88 DD Advisory Committee Members

October 1987 launched the 16th year of the Metropolitan Council's Developmental Disabilities Program. The Advisory Committee (DDAC) advises the Metropolitan Council on matters pertaining to the needs of Metropolitan Area residents who are developmentally disabled. We'd like to introduce our new DD advisory committee. Members represent both Council districts and one of the following groups--consumer (C), provider (P) and general public (GP).

Dorothy Skarnulis, Chairperson (C), District 7  
Betty Goodman, Vice-chairperson (P), District 14  
Sally Anderl (C), District 11  
Shannon McCarthy-Bicha (C), District 12  
Gerald Biese (P), District 13  
Anne Carr (P), District 4  
Karen Dove (C), District 8  
Marcia Moore-Foster (P), District 4  
Gerald Glomb (P), District 3  
Eileen Harris (P), District 11  
Steven Holmstoen (C), District 12  
Jim House (P), District 9  
Don Krefting (GP), District 10  
William Lamson (P), District 2  
Marijo McBride (P), District 15  
Renee Moen (C), District 1  
Alfred "Bud" Morin (C), District 9  
Linda Rother (C), District 15  
Eileen Schmokel (C), District 14  
Nancy Seiler (C), District 3  
Becky Smith (P), District 1  
Barbara Southworth (C), District 4  
Katherine Svanda (C), District 8  
Claudia Swanson (P), District 2  
Karen Thimm (C), District 6

## AFFIRMATIVE ACTION IN STATE GOVERNMENT

Legislation passed by the 1987 Minnesota Legislature (Chapter 232 Laws 1987: H.F.1475) significantly expands the disability levels and types covered under the service worker category to include persons with physical disabilities, mental health disabilities and mental retardation.

A landmark provision of the legislation allows up to three persons with severe disabilities and their job coach to demonstrate job competence as a unit for purposes of the on-the-job civil service examination or "700 Hour" Alternative civil service testing program. For the first time in the state's history, up to 50 full time job sharing positions within the civil service will be opened to qualified individuals with disabilities and their job coach.

Job sharing allows qualified individuals to combine their time and skills to fill one full-time position. While each employee works less than full-time, their combined job performance equals that of one full-time employee and they are expected to accomplish an equivalent amount of work. State agencies select positions for job-sharing from two sources: current vacancies and current full-time positions. Job sharers serve the probationary period required of their position in accordance with the appropriate collective bargaining agreement or compensation plan.

Job sharers receive the same hourly rate of pay as a full-time person who is at the same step in the same class as the job-sharer, including the same eligibility for increases as are available to full-time employees. Benefits such as health insurance coverage, vacation/sick leave, retirement and holiday pay are prorated. For additional information about job sharing for persons with severe disabilities contact Connie Nelson, Assistant to the Commissioner; Department of Employee Relations; 520 Lafayette Rd.; St. Paul, MN 55101; (612) 296-3095.

## REQUESTS FOR PRE-PROPOSALS: JTPA/EDUCATION

JTPA/Education Coordination activities are authorized under Section 123 of the Job Training Partnership Act. The Act appropriates funds to be utilized "to provide services to eligible participants through cooperative agreements."

In 1988, the education coordination funds will be used to serve special needs groups through cooperative

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.

agreements between service delivery areas (SDAs) and education agencies. A request for pre-proposals (RFP) is being issued to invite interested parties to submit a pre-proposal. Specifically, this solicitation seeks service delivery areas, education agencies and special needs/community groups interested in joint efforts to provide better and more comprehensive services. The intent of this RFP is to focus on the needs of one specific special needs group, unless rationale is provided for including additional groups. Funds will be available statewide to operate projects from July 1988 until June 30, 1989. Fund requests should not exceed \$70,000.

To obtain a copy of the Educational Coordination Pre-proposal application form, please contact Steve Frantz; State Board of Vocational Technical Education; (612/296-8493) or Jim Korkki; State Job Training Office; (612/296-6061).

Pre-proposals must be **received** by Arthur Vadnais, State Board of Vocational Technical Education; Suite 400 Gallery Professional Building; 17 W. Exchange St.; St. Paul, MN 55102 by **4:30 p.m., Wednesday, January 5, 1988.**

#### **FRAMEWORK FOR ACCOMPLISHMENT WORKSHOP**

For families and service providers who want to move toward an integrated service system, this FRAMEWORKS workshop will be of great value. The workshop will be presented at the Radisson University Hotel in Minneapolis from November 15-20. Jane Wells of Creative Community Options is presenting a five-day learning experience where participants will learn state-of-the-art basics for building community connections and making the community responsive to the needs of people with developmental disabilities. The participants will actually spend time with people who have disabilities as part of a working team in a cooperating human service program.

Registration fee is \$195 and covers tuition, materials, refreshment breaks and one lunch. Registration is limited to 30 people. For registration form or more information: Jane Wells; Creative Community Options; 4209 Oakmede Lane; White Bear Lake, MN 55110; (612) 426-9263.

#### **NATIONAL CENTER FOR YOUTH WITH DISABILITIES**

A new program, the National Center for Youth with Disabilities (NCYD) Adolescent Health Program is Minnesota-based and offers many resources. NCYD's purpose is to provide information, technical assistance and opportunities to network for professionals serving young people with chronic illness and disabilities.

The Center has an extensive Resource Library that is computer-based and includes information about major health and service publications, related legislation, model programs and projects and training materials that focus on youth's transition to adult functioning. In addition, its technical assistance provides consultation

on pertinent transition subjects by all major professional sectors. The NCYD fosters development of community-based services among state and federal agencies and organizations by its distribution of monographs, newsletters and by national and state workshops and conferences. For more information: Nancy Eskinow, Executive Director; NYCD; University of Minnesota; Box 721 - UMHC; Harvard Street at East River Road; Minneapolis, MN 55455; (612) 626-2825.

The NCYD is housed in the Adolescent Health Program of the University of Minnesota. It is a collaborative project with the Society for Adolescent Medicine and supported by a grant from the Division of Maternal and Child Health, U.S. Department of Health and Human Services.

#### **PARENT CASE MANAGEMENT**

The first year of the Parent Case Management Program, which was funded through grants from the Governor's Planning Council on Developmental disabilities and the Emma B. Howe Memorial Foundation ended on September 30, 1987.

In the first year of the project, 12 parents were trained and assumed the role of Parent Case Managers for their sons or daughters with developmental disabilities with support from their county case managers. A Parent Case Manager Technical Advisory Committee and four task forces have developed a number of products such as a 1,200-item library, a training package, an Individual Service Plan form, a respite voucher system and a parent/county agreement format. First year information regarding the Parent Case Management Program and relative program materials is available by calling Marijo McBride at 431-3700 or writing ARC Suburban, 14451 County Rd. 11, Burnsville, MN 55337.

October 1, 1987 the second year of the program will begin with funding through grants from the Governor's Planning Council on Developmental Disabilities, the Otto Bremer Foundation, Nevin N. Hustad Foundation for Handicapped Children and the McKnight Foundation. The second year will see expansion in the program by addition of five parents and or guardians plus consumers with volunteer mentors. The name of the program will change to "Consumer Case Managers."

#### **NEW COMPUTER RESOURCE CENTER OPENS FOR CHILDREN, YOUTH WITH DISABILITIES**

Children and youth with disabilities and their families are invited to visit the new, free computer resource center now open at PACER Center in Minneapolis. The new center will provide both parents and professionals with a place to turn for help in locating the best computer, adaptive device, and software program to meet the special needs of a child, according to Dan Berks, the center's coordinator.

PACER, a statewide information center for parents of children and youth with all disabilities, was selected a

one of 11 sites nationwide to serve as a charter member of the National Special Education Alliance (NSEA), a program funded by Apple Computers. Apple provided the new center with computers and adaptive devices.

Families coming to the Twin Cities should make sure to schedule a stop at PACER to learn about the computer technology that may have been developed for someone with their son's or daughter's handicap. Please call in advance to arrange a convenient time.

Persons not able to pay a personal visit to the center are invited to contact Berks by phone to discuss computers, adaptive devices, and special programs. PACER has a toll-free number for use exclusively by Minnesota parents of children and youth with disabilities, 1-800-53PACER.

Operating funds for the computer center are provided through the Unique Learner Section of the state's education department with additional funding provided by foundation and corporate grants and individual donations.

## **EMPLOYMENT OPPORTUNITIES**

### **Job Coach**

Flexible person with high-quality standards to train and supervise adults who are mentally retarded in community-based job stations and/or center-based work site. Full-time position.

Minimum qualifications include high school diploma or equivalent. College credits or A.A. degree preferred. Experience working with persons who are mentally retarded or industry-related job is preferred. Job description available from: Kaposia, Inc.; 179 E. Robie St.; St. Paul, MN 55107; (612) 227-9291.

## **FOR YOUR INFORMATION**

### **Assistance Available on Housing Options**

Families interested in developing their own housing for family members who are mentally retarded can now get technical assistance and information and referral on this subject from ARC Minnesota. Project Director for the Housing Options Project is Bud Morin. He can be reached at the ARC Minnesota office, 827-5641 or at his residence, 553- 9214.

### **Instruction in the Political Process**

The United Handicapped Federation (UHF) has established an "Election 88 Task Force" to offer instruction about strategies for participating in the political process and putting disability issues high on the 1988 political agenda. The task force activities will cover precinct caucuses, party conventions, voter registration, candidate forums, and get-out-the-vote strategies. Most of these activities will take place in the Twin Cities Metro Area. UHF will also provide this assistance in Rochester in conjunction with the Rochester Center for Independent Living.

People in greater Minnesota who will take responsibility to help organize and sign on at least 20 participants can request UHF to offer these activities in their localities. For more information: Tom Zosell; UHF; 1821 University Av., Suite 284-S; St. Paul, MN 55104; (612) 645-8922.

### **Scouting for Integration**

Families have to take the initiative to make integration happen. Using generic resources (those used by people without handicaps) is a place to start. Cub scout, boy scout and girl scout troops are recruiting new members this time of year.

Scouting gives boys and girls of any age the opportunity to learn more about their environment, learn new skills, and have fun with other scouts. Both programs offer a chance to expand horizons: learn to cook, find out more about animals, learn first aid, develop projects with their families and in their communities and a variety of other activities. Parents and other interested adults might consider volunteering as a group leader or as a co-leader or in some other capacity within the Boy Scout and Girl Scout organizations. For information about local troupes: East Metro: Girls (612) 227-8835; Boys (612) 224-1891. West Metro: Girls (612) 535-4602; Boys (612) 545-4550.

### **Gillette Task Force on Disabilities Seeks New Members**

The Task Force on Children with Disabilities is looking for new members. The Task Force, a consortium of parents and advocates from disability organizations, meets monthly at Gillette Children's Hospital in St. Paul to discuss issues facing young people who have disabilities and their families. Over the past seven years, the Task Force has encouraged the media to use positive terms when referring to people who have disabilities, published a directory for therapy services, and alerted parents and professionals to the importance of the early detection of hearing impairments in infants. For information call Anne Barnwell, Task Force chairperson, at (612) 646-8675.

### **Library Services for People with Hearing Impairments**

Public libraries in the Metropolitan Area are eager to serve individuals with hearing impairments. TDD users may call any of the four numbers to get answers to questions or request materials to be delivered to their nearest library:

566-2233 TDD (Brookdale - Hennepin Area Library)

830-4927 TDD (Southdale - Hennepin Area Library)

784-7013 TDD (Anoka County Library - Blaine)

372-6533 TDD (Minneapolis Public Library and

Information Center)

The 101 public libraries in the seven-county area offer books, magazines, closed caption video cassettes and a whole lot more. Please call or visit!

### **Community Transition Committees Established**

This spring the state legislature passed a statute establishing Community Transition Interagency Committees to improve services for youth and adults with disabilities beginning at age 14. A school district or

special education cooperative will be working with the county or counties to establish the committees.

The committee's mission is: to identify existing community services and programs; address students' transition needs; develop plans to meet those needs and identify any changes necessary in existing programs and services; prepare a yearly summary of the committee's work.

The long-range outcome of the transition committee's work should result in an increase of students in work experience; access to post-secondary institutes; better information on social security eligibility and parents's satisfaction with community living options.

Readers wishing to join a community transition interagency committee should contact the special education director in their school district.

## **FEDERAL HIGHLIGHTS**

### **DD Medicaid Reform Legislation**

Federal legislation that would make major changes in the way Medicaid money is used was introduced in the U.S. Senate September 10 by Sen. John Chafee. The bill, S1673, is called "Medicaid Home and Community Quality Services Act of 1987." The bill's main provisions are:

- To shift federal funding to community-based services, allowing more individuals living in institutions to receive services in their communities. Currently, Medicaid funding favors institutional services and facility-dependent, specialized services. Reforming Medicaid would provide free choice for support services selected according to what a person really needs.
- To provide a steady source of funding for families who are trying to keep their family members with disabilities at home. Services to families would be provided without "spend-down" requirements.
- To make Medicaid funding available for permanent support of other individualized community services such as living arrangements and vocational training. Since state hospitals in most states are gradually reducing their populations, steady funding would transfer to the community services most people are requesting.
- To make each state responsible for developing a plan that protects individual rights and requires Individual Habilitation Plans, case management, staff training, crisis intervention, and safeguards against abuse and neglect.
- To provide comprehensive standards for quality assurance, including monitoring requirements and funding, licensing, standard setting and independent third-party review of funded services.

Readers are encouraged to let state senators Dave Durenberger and Rudy Boschwitz know that they support this change in the Medicaid system. You can write or call them at:

Senator Dave Durenberger; 154 Russell Senate Office Bldg.; Washington, D.C. 20510; (202) 224-3244 or local (612) 370-3382.

Senator Rudy Boschwitz; 506 Hart Senate Office Bldg.; Washington, D.C. 20510; (202) 224-5641 or local (612) 221-0904.

### **P.L. 94-142--Progress Report To Congress**

More than four million children with handicaps receive special education and related services during the school year 1985-1986--an increase of 7,000 over the previous year. This is the smallest annual increase since the enactment of P.L. 94-142, Education of the Handicapped Act. Children aged 6 through 11 represent 48 percent of students receiving special education; students aged 12 through 17 represent 41 percent; and the number of students aged 3 through 5 served represent 6.3 percent.

Nearly 27 percent received special education in regular classes; 42 percent received services in resource rooms; and nearly 24 percent were placed in separate classes within regular education buildings. These facts and figures and hundreds of others are described in the recently released Ninth Annual Report to Congress on the implementation and impact of P.L. 94-142. For a free copy of the report, write to Mr. Lou Danielson; Chief, Special Studies Branch; U.S. Department of Education; OSERS/OSEP/DID; 3523 Switzer; 400 Maryland Av. SW.; Washington, D.C. 20202.

### **TECH Act Introduced**

On August 4, Sen. John Kerry (MA) introduced S.1586, Technology to Educate Children with Handicaps. The TECH Act is the first piece of federal legislation to recognize the importance of technology and assistive devices in educating individuals with handicaps. The bill would amend P.L. 94-142, Education of Handicapped Act, establishing a new fund for Assistive Device Resource Centers in all states. Senate hearings are expected next fall.

### **Catastrophic Coverage for Children**

Sen. Lowell Weicker (CT) has introduced S.1283, Medicaid Catastrophic Coverage for Children Act. It would require states to provide coverage under their Medicaid plans for children with extraordinary expenses for medical and remedial care. By use of an early periodic screening, diagnosis, and treatment (EPSDT) benefit specifically designed for children with disabling and catastrophic health care needs, an interdisciplinary care coordination team will consider each child's specific need and design and oversee health care plans. The bill includes, but is not limited to, individuals currently within the categorically needy system of Medicaid. Emphasis is placed on home care services, respite by a skilled caregiver, and home adaptive equipment.

# INFORMATION EXCHANGE

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Member of  
National Association of  
Developmental Disabilities  
Councils

November 1987

## HEARING DECISION CONFIRMS RIGHT OF ROSEMOUNT STUDENT TO ATTEND HER COMMUNITY HIGH SCHOOL

On October 8, 1987, an Administrative Law Judge ordered that a fifteen-year-old Rosemount student who has moderate-to-severe mental retardation be permitted to attend Rosemount Senior High School. The Judge determined that the District's proposal to serve the student in a special education program operated by Dakota County Intermediate School District 917 at the Dakota County Technical Institute (D.C.T.I.) would violate the student's right to attend school in the least restrictive environment. The Judge ruled that within thirty days, the School District must develop a new Individualized Education Plan (IEP) for the student which should provide for a primary placement at Rosemount Senior High School, to be blended with a partial placement at the D.C.T.I.

In a 41 page decision, the Judge emphasized that the School District had the burden of proving that the student could not be provided an appropriate program of education at the high school, and that she would be better served by removal to the D.C.T.I. The School District is required to maintain a continuum of alternative placements to the extent necessary to implement each individual student's IEP. "Merely stating that an appropriate placement is not available within the District is an insufficient response to the issue of the availability of the continuum of placement," the Judge stated. The Judge cited the legal presumption in favor of placement at the high school, and held that the School District had failed to meet this burden.

The Judge also cited the importance to this student of opportunities to participate with, and learn from, age-appropriate peers who do not have disabilities. The Judge found that the high school would provide many more opportunities for such integration. Opportunities the student would have for partial participation with her non-handicapped peers, and the importance of community-based instruction were discussed by the Judge.

Unless the School District appeals this decision within fifteen days after receiving it, it will become a final decision. As of October 16, no appeal had been filed.

For further information, contact: Larry Ringer or David Moss; Legal Advocacy for Persons with Developmental Disabilities; 222 Grain Exchange Building; 323 Fourth

Avenue South; Minneapolis, MN 55415. Tel. (612) 332-1441, or (800) 292-4150.

## MINNESOTA DD COUNCIL TRAINS PARTNERS IN POLICYMAKING

The Minnesota Governor's Planning Council on Developmental Disabilities approved funding of a second-year effort to train consumers, parents, and guardians. Partners in Policymaking is a program to provide information, training, and skill building to individuals with developmental disabilities, their parents, or guardians so that they can obtain the most appropriate state-of-the-art services for themselves and others. This is accomplished by delivering a number of two-day sessions to a limited number of highly motivated, interested individuals. Thirty-five persons are participating this year. Topics covered are: history, philosophy, values; best practices in education; policymaking at the local, county, state, and federal levels; funding, rules, laws; best practices in employment and living; nonaversive therapy; and organizations, programs, and opportunities. The overall goal is to achieve a productive partnership between people needing and using services and those in a position to make policy and law.

The program is designed to give participants exposure to, and contact with, nationally known experts in the field of developmental disabilities. Accepted applicants sign a contract which commits them to attend two-day sessions, approximately eight times a year, plus doing homework assignments. During each of the sessions, experts in specific areas present and interact with the participants. (Since May, the following persons have been presenters: Rosemary and Gunnar Dybwad, Lotte Moise, Dolores Norley, Ed Roberts, Hank Bersani, Betty Pendler, Allan Bergman, and Fran Smith.) Each session begins on Friday shortly after noon and concludes Saturday late afternoon. This allows time for the participants to converse with the experts in small groups or on a one-to-one basis. The result has been: leadership development, grass roots advocacy, the development and sharing of a collective vision of the future; the development of a reciprocal relationship between self-advocates and national leaders; and the formation of a core of spokespersons throughout the state who can address a wide range of issues.

Even the short experience to date with Partners in Policymaking has shown the value of the concept, as evidenced by the following examples:

- One participant used one of the presenters to assist

■ negotiating with the local school district for an appropriate placement for her daughter.

■ One participant applied for and was appointed to the Minnesota Special Education Advisory Council. In addition, she was able to convince the local school district to place her daughter in an integrated kindergarten in her own community.

■ Another participant met with legislative staff for several hours to discuss his son's needs.

■ Another participant spoke with the St. Paul **Pioneer Press Dispatch** to arrange a story about the Home and Community-based Waiver program.

■ Another participant approached KSTP-TV and arranged for a one-hour program about children with disabilities.

■ Another participant has recently been appointed to serve on the State Early Intervention Interagency Coordinating Council, implementing P.L. 99-457.

■ A father and his daughter with a disability are cooperating with their local newspaper to prepare a series of articles on their experiences in pioneering an integrated kindergarten classroom experience in their school.

The significance of empowering individuals through increased knowledge and self-confidence is reflected in the following sample statements by individuals who participate in Partners in Policymaking:

■ My twin sons, both having disabilities, have responded wonderfully to the educational and medical interventions that have been provided since I wrote to the Governor three years ago in desperation. Their development into individual, well-rounded persons is a difficult thing to quantify. However, in our minds is the result of our belief in their individual potentials and our acceptance of their limitations. This attitude and commitment has been echoed in the numerous individuals who have helped us in our endeavors.

There are many stresses involved in raising children with special needs. With support, including community acceptance, the children can be accepted into the "normal" community as productive members. Professionals dealing with families of children with special needs should work with the parents as equals but also realize that support is needed to maintain normalcy. By hearing actual situations, it may help the professionals put their acquired knowledge into perspective with what actually happens and will add an added dimension to their understanding of the complexity of daily life.

Our children with disabilities, if given the chance will be able to give more back to the communities, to the work force and to the voting arena. To do this they need, we as parents need, support, including physical, social, technical, and financial.

Partners in Policymaking is needed throughout the country. We parents need to advocate for our children. To be effective we must have the knowledge and the skills to communicate at the same level as the people

we need to work with to promote and make change. Participating in Partners in Policymaking has helped me to become a more independent, knowledgeable advocate for my child--to work with public officials to make policy changes so that all children and adults with special needs may benefit.

For more information, contact: Ron Kaliszewski, Minnesota Governor's Planning Council on Developmental Disabilities, 300 Centennial Office Building, 658 Cedar Street, St. Paul, MN 55155. Tel. (612) 296-4018.

## **GREATER MINNESOTA TO BENEFIT FROM PROJECTS WITH INDUSTRY GRANT**

The Minnesota Division of Rehabilitation Services (DRS), Department of Jobs and Training, was awarded a three-year Projects with Industry Grant by the Rehabilitation Services Administration, effective October 1, 1987. The purpose of this Projects with Industry (PWI) grant is to expand job opportunities in Greater Minnesota (non-metro areas) for students with severe disabilities who are making the transition from school to competitive employment. Grant funds of \$141,000 the first year will allow DRS to hire six new staff members to provide PWI services. A Business Advisory Council will be established in each of the three rural DRS service areas where the Project will be located to advise the PWI staff on local employment needs. Through the combined efforts of the business community and the rehabilitation community, DRS anticipates being able to significantly increase the number of students with severe disabilities who are placed in competitive employment in the community. For more information, contact Jim House, Division of Rehabilitation Services, Department of Jobs and Training, 390 North Robert Street, St. Paul, MN. Tel. (612) 296-5622.

## **SUPPORTED EMPLOYMENT WORKSHOPS SCHEDULED BY PACER**

**Supported Employment Workshops**, intended for parents of older students and adults with disabilities, will be sponsored by the Parent Advocacy Coalition for Educational Rights, Inc. (PACER). These workshops are presented as part of a contract with the Minnesota Supported Employment Project of the Department of Jobs and Training and the McKnight Foundation. Supported employment is an adult service program that provides ongoing support to persons with severe disabilities enabling them to work in regular jobs within the community.

The first eight workshops will be three hours in length, and will be held between 7:00 and 10:00 p.m. The last four workshops will be more in-depth and comprehensive, and will likely occur over a two-day period. The tentative schedule of workshops throughout the state are as follows:

October 20--Stillwater  
 November 4--Eveleth  
 November 17--Bemidji  
 December 1--Marshall  
 January (late)--Shakopee  
 February (early)--Hinckley  
 February (late)--Red Wing  
 March (early)--Brainerd  
 March (late)--Rochester  
 April (early)--Mankato  
 April (late)--Twin Cities  
 May--Fergus Falls

For more information, contact: Cathleen Urbain; PACER Center; 4826 Chicago Avenue, South; Minneapolis, MN 55417-1055. Tel. (612) 827-2966.

## A STORY THAT I HEARD

The following selections are 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:

### GOVERNMENT ANTI-LONELINESS PROJECT

**Bill Madiera**

During World War II in England, people who could prove they were widowed or handicapped and alone could get a parakeet and a monthly stipend for birdseed from the government to keep them company.

### MEDICAL ADVICE

**David B. Schwartz**

My wife, Beth, met Eli Wickham, an elderly neighbor of ours, at the Volunteer Firemen's Pancake Breakfast. He was having a second pancake at one of the long tables across from her, and was telling her about himself. One of the problems that he had been having was that he had been steadily losing weight, to the point that he was very thin and frail. He went to his doctor--and what did his doctor do? He asked him if he ate alone! Sure, I eat alone all of the time, old Mr. Wickham told him. Well, you shouldn't do that, the doctor told him. Make sure that you always eat with somebody else. So I did, Mr. Wickham told my wife. And you know, it worked!

### WANDERER

**Reg Bould**

What do you search for  
 In your bits of paper,  
 string and trivia?  
 Do you seek to find yourself  
 who seems to slip away  
 a little more each day?  
 Or do you want to lose  
 that self whose painful presence  
 you cannot bear?  
 Who can guide us?  
 We and you,  
 Tell us truly, what to do  
 to bring together  
 You and You.

## PUBLICATION

**Family State-of-the-Art Conference: A Summary of Conference Proceedings**, prepared by Ann Turnbull and Harriet Shaffer, Georgetown University Child Development Center, 1986. In an effort to discern what

families actually need to help them maintain a successful and quality family life, the National Institute on Disability and Rehabilitation Research, within the Office of Special Education and Rehabilitative Services, convened a group of individuals specifically concerned with special needs families at Alexandria, Virginia, on February 27 and 28, 1986. The discussions focused on the positive aspects of knowing, living with, and loving a child or an adult with a disability. This meeting was different from others that have dealt with the family because it highlighted the strengths of people with disabilities.

The participants set forth statements of what families with special needs want from the various service systems on which they depend, particularly the availability of more integrated educational, recreational, and vocational opportunities. The group made recommendations regarding ways in which service providers and policy makers could be more responsive to the goals, values, and desires of people with disabilities and their families. This responsiveness involves issues such as accepting families' and consumers' desires for placements in integrated settings, flexibility in guidelines for funding services, and allowing families to decide which services they actually want to use.

Content of the **Conference Proceedings** is categorized into five major family life functioning areas: 1) daily living and health needs; 2) educational and vocational needs; 3) financial, legal, and advocacy needs; 4) socialization, leisure, and sexuality needs; and 5) emotional needs. Bases for recommendations were built upon the following premises:

1. Disability creates special needs in all areas of family life.
2. Individuals with a disability make positive contributions to their families.
3. Families have individualized needs requiring individualized responses from an array of appropriate services.
4. Family needs should be met within integrated community services and environments.
5. Families should have access to information.
6. Families need to expect confidently that their member with a disability will have a positive future.
7. Strategies for enhancing family life must be cost-effective.

Ann Turnbull, who prepared this publication, concluded: "Whether a strategy is as specific as 'provide tax incentives to industries who employ persons with disabilities' or as general as 'display love and affection towards the individual with a disability as with any family member, our goal is the same: **To enhance family life where there is a member with a disability.** When groups do implement these strategies, we will move closer to the enhancement of family life for particular families and for our society as a whole." Copies may be requested from: National Center for Networking Community Based Services; Georgetown University Child Development Center; 3800 Reservoir Road, NW; Washington, D.C. 20007. Tel. (202) 625-7675.

## 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.**

**Supported Employment Strategies Manual**, C. French, Government Training Service, 1987. This training manual was developed under contract with the Minnesota Supported Employment Project, and is intended to help the reader understand some general issues relating to supported employment, as well as to assist service providers to develop such programs in their communities. Content includes: values clarification; definitions and organizational structures; getting started--administrative issues; missions, goals, and objectives; securing jobs for supported employment; conducting a job analysis; assessment--purposes and procedures; on the job training; and maintaining supported employment. The appendix contains: sample brochures to solicit jobs; samples of generic work skills; sample task analyses; Huron Vocational Assessment Instrument; and selected readings. With the implementation of this new service comes rapid changes, the author notes, "but we need to put (such change) into a proper perspective and view them as 'challenges.'"

**Cognitive Counseling and Persons with Special Needs: Adapting Behavioral Approaches to the Social Context**, Herbert Lovett, Praeger Publishers, 1985. This book describes the effective and humane use of behavioral methods to teach social and cognitive skills to persons with severe and profound levels of mental retardation. It serves as an introduction and guidebook that outlines general principles and case studies to illustrate the concepts under discussion. This book offers readers sound professional advice as well as emotional support and inspiration. For example, Lovett observed: "...our perceptions and assessments of a persons's abilities can become self-fulfilling prophecies. When we assume that individuals can learn to do anything, regardless of the label or presumed disability, then we are leaving it up to them to tell us their limits. For years we have defined the ceiling of capability for an entire population of our fellow citizens by saying, They will be able to do this much and no more. And when we do not give them the opportunity to do more, the prophecy always comes true. Only when the lives of all allow the maximum opportunity for development will we know what an individual can really do."

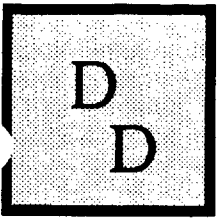
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# INFORMATION EXCHANGE



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## METROPOLITAN COUNCIL DD PROGRAM NEWS

You may be unaware or have forgotten that the 1980s were proclaimed by the President as the **Decade of Disabled Persons**. As the decade moves forward, it may not be too early to engage in retrospection about what has happened to advance the rights of people with disabilities. Starting in 1980, several major federal laws were passed:

- 1980. Social Security Amendments (PL 96-265, Sections 1619 a and b). Established a three-year demonstration project giving people with developmental disabilities continued benefits even when earning wages. (1987. Made these benefits an entitlement.)
- 1981. Omnibus Reconciliation Act (PL 97-35, Section 1176). Allowed states to use the **Home and Community Based Waiver** as an alternative to ICFs-MR.
- 1982. Social Security Amendments (PL 97-248). The so-called **Katie Beckett Amendments** permitted states to use Medicaid funds for certain children (18 and under) with disabilities who were living at home.
- 1983. Education Amendments (PL 98-199). Established and funded **transition** services for students with disabilities moving from school to work.
- 1984. Carl Perkins Vocational Technical Education Act (PL 98-524). Required development of quality vocational education and expansion of existing programs and setting aside 10% of VTE funds specifically for people with disabilities.
- 1984. Child Abuse Amendments (PL 98-457). Mandated reporting of medical neglect if treatment is withheld from infants with disabilities.
- 1986. Education of All Handicapped Children Amendments (PL 99-457). Amended PL 94-142 and mandated pre-school programs for children (3-5 years) and planning for early intervention programs for younger children with disabilities.

Minnesota laws included:

- 1981. Vulnerable Adults Protection Act. Gave special protection to adults against abuse and neglect; requires reports by professionals and employees of suspected violations.
- 1981. Case Management for People with Mental Retardation (and Other Related Conditions/1985). Made

county case management mandatory and established standards for counties to observe in providing case management.

- 1983. Semi-Independent Living Services. Provided grants to counties to provide supervised services to people with disabilities who need less than the continuous and daily supervision provided by ICFs-MR.
- 1985. Other Related Conditions Act. Mandated that services similar to those received by people who are retarded, be provided for people with autism, cerebral palsy and epilepsy. Deleted out-of-date and demeaning language in laws relating to people with mental retardation or mental illness.
- 1985. Interagency Office of Transition Services. Established transition services in Minnesota Department of Education.

Court actions in other states and in Minnesota also signaled changes this decade. In 1982, the U.S. Supreme Court ruled for the **right to treatment** in the famous Pennhurst case in Pennsylvania. In 1987, the Minnesota class action suit (Welsch v Likins) that began in 1974, was finally settled. This case established the **right to treatment in the least restrictive environment** for persons with mental retardation who live in state institutions.

A retrospective view would permit looking back several decades. The other "rights" movements cannot escape comparison: unions in the thirties, civil rights for black people in the sixties and for women in the seventies. While each movement has distinctive characteristics, it also has many similarities. In each of the earlier movements, there was ever expanding, but painfully slow awareness of the nature and extent of the deprivation of human and civil rights and degradation suffered by people deprived of those rights.

Last summer a seminar was held on the topic, *What Are the Lessons from the Civil Rights and Women's Movements for Expanding Participation of Persons with Disabilities in American Society?* There were four prominent panelists. Some of their most pertinent remarks are paraphrased below:

- Each of the rights movements has to do with the rights of being human, without regard to variations

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.

among human beings....What the civil rights movement was about was expanding the protection of democracy to those who were being denied such opportunity. (Dr. Kenneth Clark, civil rights leader and professor emeritus, City University of New York.)

■ Any social movement needs several elements to be successful: an ideology that justifies change (i.e. a cause you really believe in), committed leaders who can work together, an effective communication system and political know-how. (Dr. Anne Firor Scott, leading authority in the women's movement and professor of history, Duke University.)

■ There is a necessity (in social movements) for society to decide that there is something morally wrong and to get power relationships to change. (Dr. Philip Calkins, historian and national coordinator of a voter registration drive for persons with disabilities.)

■ Blacks and women made progress because they could lay claim to natural and Constitutional rights...the handicapped community's claims are not based on these rights. Rather than taking "rights" as the foundation for change, the fundamental task should be to sensitize society to the discrimination that disabled people face...to temper the language of rights and "supplant it by the language of moral appeal to community benevolence." (George F. Will, nationally syndicated columnist and parent of a child with disabilities.)

Several people took issue with Mr. Will's remarks. Dr. Calkins, one of the panelists, stated that "benevolence" does not exist (everywhere) in today's world and that is why appeals based on rights, such as the 1964 Civil Rights Act, are vital. In that law the section on public accommodations was intended to change discriminatory behavior and it did. Society does not give the same kind of benevolence to certain people and benevolence can be withdrawn on any whim, which is why laws based on rights are necessary.

A member of the audience, Harry Hall, made this statement.

"The historical perspective of both the women's movement and the civil rights movement is that there was an assertion that there are rights, which were not accepted despite the fact that we had a Constitution and a sense of what is liberty and what is justice to individuals. And it seems to me that the core of the disability rights movement is to say to those who do not think there are rights, that this issue is about rights. We intend to make it an issue of rights, and what was not before (sic) rights will become rights for disabled people, as occurred for women and other minorities."

The **Decade of Disabled People** has seen major progress. Yet major needs remain: educating the public (including some parents!) and moving from values to action. There is a giant constituency for people with disabilities: the individuals who are disabled, their families, siblings and other relatives, professionals and others who supply services, and other concerned members of the public. The majority, if asked, would favor a human and civil rights movement for people with handicaps. Yet this giant continues its mass inertia.

It does not use the political process: writing or calling relevant legislators, public officials, administrative agencies to voice its views. It seldom uses personal initiatives to respond to newspapers or other media that support or thwart the rights of people with disabilities to have equal opportunity to live in real homes, work in real jobs and access resources provided for other citizens. Can each reader say she or he has taken one such action this year to better the quality of life for people with disabilities?

As one civil rights leader said, "If you are not part of the solution, you are part of the problem." The **Decade of Disabled People** is the concern of each of us.

### Library Additions

The following recently published books have been added to the DD Curriculum Library of the Metropolitan Council:

Evans, Ian M. and Meyer, Luanna H.; **An Educative Approach to Behavior Problems: A Practical Decision Model for Interventions with Severely Handicapped Learners.**

Falvey, Mary A.; **Community-Based Curriculum: Instructional Strategies for Students with Severe Handicaps.**

Gardner, James F. and Chapman, Michael S.; **Staff Development in Mental Retardation Services: A Practical Handbook.**

Horner, Robert H., Meyer, Luanna H., Fredericks, H.D. (Bud); **Education of Learners with Severe Handicaps: Exemplary Service Strategies.**

Lakin, K. Charlie and Bruininks, Robert H.; **Strategies for Achieving Community Integration of Developmentally Disabled Citizens.**

Popovich, Dorothy; **Effective Education and Behavioral Programming for Severely and Profoundly Handicapped Students.**

Most of these books have been reviewed in this publication. Books may be borrowed by Metro Area residents only. The books are available, free of charge, for up to three weeks. Please call 291-6364 to make sure someone is available to sign-out books. Readers in Greater Minnesota can use library resources provided by the State DD Program Office, Centennial Office Building. (See the last page of this newsletter.)

### RESOURCES/SERVICES

#### Transitional Program for People with Epilepsy

S.E.A.R.C.H. (Serving Epilepsy as A Related Condition in Housing) is a new transitional program designed to teach people with epilepsy the social, vocational and daily living skills necessary for independent living in the community. Program participants will receive monitoring and habilitation from SEARCH while living in apartments

managed by the Minneapolis Community Development Agency. It closely follows the model provided by People House, a group home in south Minneapolis that operated for seven years with great success before closing in August of 1987 due to changes in group home (ICF-MR) eligibility regulations.

This program will be managed by People Incorporated. The tentative starting date is January 1, 1988. If you want more information or would like to make a referral, please contact Glen Anderson, Executive Director of People, Inc. at (612) 224-7639 or Anne Barnwell at the Epilepsy Foundation of Minnesota: 1-800-292-7932 or 612/646-8675.

### **Free Computer Materials**

A free packet of materials on using Apple computers with children and adults with disabilities is available. The packet includes information about talking and large-print Apple software, accessories, and peripherals. It also includes information about special hardware such as keyboard adaptations. Requests should state the individual's disability, developmental or age level, interests and needs, and information about the kind of equipment needed. Products are being used by persons with vision impairments, multiple handicaps, mental retardation, and learning disabilities. Write to Unlimited-SPEECH Enterprises; P.O. Box 7986; Houston, TX 77270 or call toll-free 1-800-531-5314.

### **New Evaluation Clinic**

The Courage Evaluation Clinic for Children and Families offers a unique service where parents and specialists work together to identify and make recommendations for infants, toddlers and children of all ages who are at risk, disabled or delayed in their development. This new clinic can offer:

- an "entree" into medical therapy services
- an evaluation to qualify for special education services
- recommendation for an IFSP or IEP
- an evaluation to complement an existing therapy program
- an evaluation of complex therapy needs
- additional resource for programming suggestions.

The fees are billed to third party sources when appropriate and adjusted fees are available. Referrals may be made by parents, health/education/social service agencies. A physician's order is needed to complete the referral. For more information: Courage Center; Admissions Coordinator; 3915 Golden Valley Road; Golden Valley, MN 55422; (612) 588-0811, ext. 152.

### **FOR YOUR INFORMATION**

#### **Case Management Compliance Meeting**

Parents living in Hennepin County are invited to meet on Tuesday, December 15, to address concerns about that county's compliance with Rule 185 (regulations

addressing case management standards and responsibilities for counties). A new task force of ARC of Hennepin County will review what Rule 185 requires of counties, whether Hennepin County is in compliance and determine what strategies will direct the county into full compliance. Parents are especially encouraged to attend on Tuesday, December 15, 10 am to noon at the office of ARC Hennepin County; 2344 Nicollet Avenue South; Minneapolis. For more information, call (612) 874-6650.

### **Financial Resource**

*"Revolving Loan Funds: Expanding Equipment Credit Financing Opportunities for People with Disabilities."* Resource document available at no cost which discusses revolving loan funds to help finance acquisition of assistive aids and devices. Rehabilitation Engineering Center; 1901 Pennsylvania Ave., N.W.; Suite 700; Washington, D.C. 20006; (202) 955-5822.

### **New Clearinghouse**

The National Clearinghouse on Women and Girls with Disabilities has been established by Educational Equity Concepts, Inc. It will create a computerized, systematic means of gathering information, providing resources and references, developing a communications network and conducting public education regarding women and girls with disabilities. Contact: The Clearinghouse at 114 East 32 Street; New York, NY 10016; (212) 725-1803.

### **Tele-Consumer Hotline**

The Washington, DC Tele-Consumer Hotline has recently published a **Shoppers' Guide** listing equipment specifically designed to help consumers with speech, vision, hearing or mobility impairments use the telephone. Operates 9 a.m. to 5 p.m. (EST), Monday through Friday. 1 (800) 332-1124; V/TDD outside Washington, D.C.

### **First International Conference on Family Support**

The Institute for Integration invites all persons involved with families who have a severely disabled family member to the First International Conference on Family Support. The conference will be held at the Sheraton Stockholm Hotel in Sweden, August 14-18, 1988. For more information: Conference Secretariat; Family Support 88; c/o Congrex; P.O. Box 5619; 114 86 Stockholm, Sweden; Telephone : +46 8 723 42 30; Telex: 16949 KRECON S.

### **Job Bias Hotline**

Job seekers with disabilities and their advocates can obtain answers to questions about job discrimination laws from Equal Employment Opportunity Commission (EEOC); Washington, D.C.; 1(800) USA-EEOC.

### **Clothes Catalog**

**Special Clothes** is a catalog featuring current design

and easy-care clothes that allow for some specific needs of children with a variety of physical disabilities. The catalog is free and may be obtained by writing or calling: SPECIAL CLOTHES; P.O. Box 4220; Alexandria, VA 22303; (703) 549-2640.

### **Artwork Sought for Spring Exhibit**

Artists with a disability are invited to enter their artworks in the 25th Annual Sister Kenny Institute International Art Show by Disabled Artists. Artworks should be sent to the Sister Kenny Institute in Minneapolis no later than February 28, 1988.

Any artist with a physical or mental disability which limits one or more major life activities (such as caring for oneself, performing manual tasks, walking, seeing, hearing, breathing, learning or working) is eligible to enter up to two pieces of art. All media are accepted including oils, acrylics, pen and ink, watercolors, pastels, sculpture and photography. Cash prizes will be awarded to artworks judged best in their category.

Artworks will be on sale during the Art Show Grand Opening on Friday, April 15, and while the works are on display through May 13, 1988, at the Sister Kenny Institute. Artists price their own entries and receive the proceeds (minus a 20% commission which covers the Art Show expenses). There is no minimum price requirement, but the majority of works which sold last year were in the \$5-\$100 range. Maximum price range has been set at \$1,000. Items not for sale are accepted and included in the judging for awards and prize money.

The Art Show is co-sponsored by the Abbott-Northwestern-Sister Kenny (ANSK) Auxiliary and the Sister Kenny Institute. For information: Art Show, Public Relations Department, Sister Kenny Institute; 800 E. 28th Street at Chicago Avenue; Minneapolis, MN 55407 USA; (612) 863-4482.

### **Holiday Retreats Slated**

Holiday retreats and respite weekends for children and adults with mental retardation or developmental disabilities are being offered at Eden Wood Camping and Retreat Center, a United Way supported program, in Eden Prairie. The schedule features a range of choices from a New Year's overnight to a six-day retreat after Christmas. A January weekend at a Minneapolis hotel is also slated for adults. Respite weekends, open to both children and adults, are scheduled each month through next May. Program fees include lodging, meals, recreation programs and around-the-clock staffing. For a brochure with registration information, call or write: Association for Retarded Citizens of Hennepin County; 2344 Nicollet Avenue, So., #370; Minneapolis, MN 55404; (612) 874-6650.

### **PUBLICATIONS**

**The Guide to Human Services in Minnesota** is now available listing over 1000 services for people with chemical dependency, developmental disabilities, mental

retardation, mental illness, cerebral palsy and those who are emotionally disturbed. Most Twin City nursing homes are also listed. Other services are included relating to adolescent care, sexual abuse and assault. Many characteristics for each service are included: the name of the person to contact when seeking employment at the particular service, number of male staff, number of female clients, type of license, funding sources, county location, behavior level of clients, functioning level of clients, number of beds, name of director, a brief summary of the program and more. The cost of this valuable guide is \$15.50. Send check or money order to: JAZMYN PUBLICATIONS; P.O. Box 4213; Minneapolis, MN 55414; (612) 379-5367. Member of the Better Business Bureau.

**Simple Solutions to Difficult Problems of Handicap Access** is a catalog of products such as door levers, parking signs, chair lifts, and grab bars. It also provides a photo of the product, its approximate price, and information on where it can be obtained. One section covers "tricks of the trade" solutions to many common problems of access, e.g. door opening too narrow. Rather than remove an existing door, door frame, or widen the door - (\$1,000), often the hinge can be replaced with new "swing clear" hinges - (approximately \$60) and obtain the same outcome. It does not cover personal aids, e.g. reachers, wheelchairs, or similar type devices. Rather, it is a catalog of hardware and equipment for structural barrier removal to aid in design and construction of public building and residential homes.

To order, send \$35 (includes postage and handling in USA) to: Julee Quarve-Peterson, Inc.; P.O. Box 28903; Crystal, MN 55428. For more information: (612) 553-1246. Allow 3-4 weeks for delivery.

### **EMPLOYMENT OPPORTUNITIES**

#### **■ Program Manager**

Catholic Charities of the Archdiocese of St. Paul and Minneapolis is seeking a program manager to promote fuller participation of people with disabilities in parish and archdiocesan activities. Half-time position, \$9,110 plus pro-rated benefits. For more information about position and qualifications: Alaina Hagen; Catholic Charities; Office for Social Justice; 328 West Sixth Street; St. Paul, MN 55102; (612) 291-4483. Applications/resumes must be received by 4:30 p.m., December 18, 1987. Catholic Charities is an Equal Opportunity Employer.

#### **■ Live-in Professional(s) for one-person SLS.**

Should be energetic, compassionate and progressive. Private social service agency seeking 1-2 people to live with a woman with developmental disabilities in St. Paul. Responsible for supervision and skill development. Room/board plus excellent salary. Must have experience in MR field. For more information: Barbara; (612) 776-5401.

# INFORMATION EXCHANGE

STATE  
SUPPLEMENT

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Developmental Disabilities  
Councils

December 1987

## **PRESIDENT REAGAN SIGNS DEVELOPMENTAL DISABILITIES AMENDMENTS OF 1987; SUPPORT TO FAMILIES EMPHASIZED**

On October 30, 1987, President Ronald Reagan signed into law the Developmental Disabilities Assistance and Bill of Rights Act with amendments (P.L. 100-146). Programs authorized by the Act include: 1) formula grants to states; 2) grants to support protection and advocacy systems; 3) grants to university affiliated facilities; and 4) grants for special projects. This article will cover only those aspects affecting the formula grants to states and the activities of the State Planning Councils. Information about the other programs under the Act may be requested, as indicated at the end of the article.

The purposes of the Act are: 1) to provide assistance to states and public and private nonprofit agencies and organizations to assure that all persons with developmental disabilities receive the services and other assistance and opportunities necessary to enable such persons to achieve their maximum potential through increased independence, productivity, and integration into the community; 2) to enhance the role of the family in assisting persons with developmental disabilities to achieve their maximum potential; and 3) to ensure the protection of the legal and human rights of persons with developmental disabilities.

The new legislation places special emphasis on family support services because family and members of the community can play a central role in enhancing the lives of persons with developmental disabilities, especially when the family is provided with necessary support services. In recognition of this, priority area activities will now not only enhance services for persons with developmental disabilities but also address the needs of their families. State Planning Councils will be required to include family support service activities in their annual reports.

Under the terms of the new legislation, family support services means services designed to: 1) strengthen the family's role as primary caregivers; 2) prevent inappropriate out-of-home placements and maintain family unity; and 3) reunite families with members who have been placed out of the home including respite care, personal care, parent training, and counseling support for parents who are elderly and other individualized services.

## **Priority Area Activities**

Federal priority areas are: community living activities, employment activities, child development activities, and case management activities. A state priority area includes, at the discretion of the State Planning Council, priority area activities in two or more federal priority areas or priority area activities in an area in the state considered essential by the State Planning Council. This definition is intended to provide flexibility to the State Council to include, at its discretion, an additional focus to the basic state grant. Sixty-five percent of the basic state grant must be expended for priority area activities. Federal and state priority area activities, as spelled out in the new legislation, 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 recommendations;
- 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 area, including access to specialized services or special adaptations of generic services;
- Training of persons with developmental disabilities, family members, and personnel including professionals, paraprofessionals, 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.

## **State Planning Councils**

Members of the State Planning Councils are appointed by the Governor, and the new legislation mandates certain representation on the Councils:

- Representatives of principal state agencies including the state agency that administers funds provided under:
  - the Rehabilitation Act of 1973,
  - the Education of the Handicapped Act,
  - the Older Americans Act of 1965, and

- Title XIX (Medicaid);
- Higher education training facilities;
- University Affiliated Program or satellite center in the state;
- The state protection and advocacy system; and
- Local agencies and nongovernmental agencies and private nonprofit groups concerned with services for persons with developmental disabilities in that state.

Additionally, at least one-half of the membership of each State Planning Council shall consist of persons with developmental disabilities, parents or guardians of such persons; and immediate relatives or guardians of persons with mentally impairing developmental disabilities.

The law is amended to specify that a State Planning Council may be the designated administrative agency, if congruent with state law, and that each State Planning Council may prepare and approve a budget using amounts paid to the state under the Basic Grant to hire staff and obtain the services of professional, technical, and clerical personnel as the Planning Council determines to be necessary to carry out its functions. The staff and other personnel of a state Planning Council, while working for the State Planning Council, shall be responsible solely for assisting the Council in carrying out its duties and shall not be assigned duties by the designated state agency or any other agency or office of the state.

### Reports for Governors

Each State Planning Council will be required to conduct a review and analysis preparatory to a comprehensive report to the Governor by January 1, 1990. Councils will first conduct a review and analysis of the eligibility for services provided and the extent, scope, and effectiveness of services provided and functions performed by all state agencies (including agencies which provide public assistance) which affect the ability of persons with developmental disabilities to achieve the goals of independence, productivity, and integration into the community. Each Council shall also conduct a review and analysis of the effectiveness of, and consumer satisfaction with, the functions performed by, and services provided or paid for from federal and state funds by, each of the state agencies responsible for performing functions for, and providing services to, all persons with developmental disabilities in the state. The Councils will then convene public forums to receive comments on the review and analysis before reporting to their Governors.

### State Plan

State plans are to be reviewed and revised at least once every three years and must include:

- Analysis of priority areas in relation to limited support for persons with developmental disabilities, mental impairment, or a combination of physical and mental impairments;
- Analysis of criteria for eligibility for services, including specialized services and special adaptation of

generic services provided by agencies within the state that may be causing persons with developmental disabilities to be excluded from receiving such services;

- Analysis of existing and projected fiscal resources;
- Analysis of any other issues identified by the State Planning Councils, and
- Formulation of objectives in both policy reform and service demonstration to address these issues for all subpopulations of persons with developmental disabilities which may be identified by the State Planning Councils.

For more information, particularly about those programs not covered in this article (i.e., the university affiliated programs, protection and advocacy, and special project grants) and for copies of the Act, please contact: Minnesota Governor's Planning Council on Developmental Disabilities; 300 Centennial Office Building; 658 Cedar Street; St. Paul, MN 55155. Tel. (512) 296-4018 (voice), or (612) 296-9962 (voice or TDD).

### HOW DO WE KNOW WHEN WE HAVE COMMUNITY?

The following thoughts are those of John McKnight's (of Northwestern University, Evanston, Illinois) as expressed by Dave Wetherow (of Prairie Housing Cooperative in Winnipeg, Canada) at the "Cooperative Housing" Conference held at Elizabethtown College in Pennsylvania on December 5 and 6, 1986:

- The individual person, in relationship with another person, is at the center, not an agency.
- There is quick response to human needs, literally within minutes, with one person responding to another in times of need. Systems take days, weeks, forever, if ever.
- People thrive on stories about changes in people's lives, not studies of data.
- We depend on celebrations and personal accomplishments (achieved in relationships), instead of unnecessary paperwork.
- The most important things are informal, instead of emphasis on formality.
- Who we are is defined by who we are as people, instead of by titles on an organizational chart.
- Efforts are based on capacities of what people **can** do, **can** give, **can** learn, instead of deficiencies which concentrate on measuring what people can't do, can't give, and can't learn.
- We are all, handicapped or not, citizens, not clients or consumers.
- Decisions are made by consent, not control. Emphasis is on consensus instead of simply "getting things done" through exercise of power.
- There is real caring, not "service." Caring means the willingness to walk in the life of another person, sharing another's sufferings and joys. Service systems cannot tolerate suffering and do not understand joy. A system can't stand tragedy (ironically, systems are tragic).
- In community, we see the gifts of all people; bureaucracies see people with handicaps as a collection of chores to be accomplished.
- In community, we work **with** people. Systems work **on** people.

Dave Wetherow ended his presentation by saying, "I am extremely excited about these possibilities for the future. Right now, these are hopes and dreams, which I hope we can share. God willing we **can** and we **will** make these dreams come true.

### **A STORY THAT I HEARD**

The following selections are 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:

#### **HOLDING HANDS FOR THE FIRST TIME**

by Chris Barton<sup>1</sup>

When I was eight years old, my parents enrolled me in an elementary school which had an integrated special education curriculum. We shared such classes as music, gym, and recess with kids from the special class. One semester our gym teacher decided to teach the entire second grade class some circle dances. Now, the first step in any circle dance is to form a circle. This is easier said than done when fifty second graders are involved! It soon became clear to me that I was going to have to hold hands with Eric, a ten-year-old boy who had been severely burned in a house fire. He literally had half a face and three malformed fingers on each hand. It was up to me to hold those stubs, or the circle would be incomplete. Me, who still had nightmares of creatures that looked very much like Eric. As it turned out, I didn't have to make that decision because, as we got closer, he reached out and grabbed my hand! "Hi, I'm Eric. What's your name?" he squealed. As soon as I realized he was a normal, talking human being the fear left. For every gym period thereafter, we "arranged" ourselves in the circle so we'd be partners.

That friendship continued through the sixth grade when Eric died from complications of his burns. But it might have been that experience which prompted me to volunteer with that program during high school and, ultimately, to work in special education.

<sup>1</sup>Chris Barton is a Registered Music Therapist currently with the Farmington and Monroe Special Education Programs, where she works primarily with children with autism. She is also a member of the SongSisters, a performance duo specializing in children's music.

### **PUBLICATIONS**

**Improving Health Care for Children with Chronic Conditions: Guidelines for Families**, Alfred Healy and J. Arline Lewis-Beck, University of Iowa, 1987. This book was a result of the Iowa Health Care Guidelines Project, and offers a family-centered approach as a model for improved health care services. It is highly recommended by the Association for Retarded Citizens of the United States. The cost is \$2.50, and checks should be made payable to the University of Iowa. Order from: Campus Stores; 208 G.S.G.; University of Iowa; Iowa City, Iowa 52242.

**Family Support Bulletin**, United Cerebral Palsy Associations (UCPA). This is a quarterly newsletter that was initiated this past summer. Its purposes are: 1) to be a source of current information, research, policy, and practice at the local, state, and federal levels regarding supporting families (natural, adoptive, and foster) to raise their children with severe disabilities and/or chronic health needs in their own home; 2) to gather and share comments, articles, successes and failures in family support services from which everyone can learn; and 3) to develop a national network of families, friends, providers, government agency officials, and elected policy makers committed to assuring the development of consistent policies in the private and public sector which support families. Allan Bergman, Advocacy Liaison Coordinator for UCPA, commented in the first edition, "Family support is common sense. Family support is sound financial policy. Family support is reinforcing the family as a foundation of our society. Family support is the empowerment of families to choices and control over their destiny." Free subscriptions are available from: **Family Support Bulletin**; UCPA Governmental Activities Office; 1522 "K" Street, NW, Suite 1112; Washington, DC 20005.

**Discover the Possibilities: Transition Planning to Live and to Work in the Community** (videotape), Minnesota Department of Education, 1987. This videotape production introduces new legislation in Minnesota on transition planning for youth with disabilities. It addresses the importance of quality, early planning of movement from secondary education to postsecondary education and training, employment, and community living. The intended audiences are special education staff, parents, adult service providers, and other citizens interested in learning about transition planning for students receiving special education services. Highlights of the video include: 1) an Individual Educational Plan meeting; 2) transition planning areas; 3) students receiving community instruction; 4) students learning practical, functional skills; 5) cooperation between service agencies; and 6) parent and student participation. **Discover the Possibilities** videotapes are available through local Educational Cooperative Service Unit (ECSU) Directors or may be purchased from: Bill Schragg, Coordinator; Osseo Audio-Visual Department; Educational Service Center; 11200-93rd Avenue, N.; Maple Grove, MN 55369. Tel. (612) 425-4131. A copy is also available on loan from the Governor's Planning Council on Developmental Disabilities by calling (612) 296-4018 (voice), or (612) 296-9962 (voice or TDD).

### **HOTLINE FOR EMPLOYERS AVAILABLE**

The President's Committee on Employment of the Handicapped has a toll-free computerized information service to help employers accommodate workers with disabilities by providing names and phone numbers of successful employers and information on adaptive devices for the workplace. Call: (800) JAN-PCEH.



## 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.**

**Getting Employed, Staying Employed: Job Development and Training for Persons with Severe Handicaps**, C. S. McLoughlin, J.B. Garner, and M. Callahan, Paul H. Brookes Publishing Company, 1987. The central thesis of this book reflects the authors' firm beliefs--that human service personnel have an obligation through effective instructional strategies to encourage a new generation of workers with disabilities in integrated work settings. They state, "The undeniable conclusion is that there is no substitute for quality preparation when facilitating integrated employment opportunities for persons with severe handicaps. Quality training, as demonstrated by the learner's increased skills and competencies, is the necessary ingredient for integrated employment. Employment preparation involves sound analyses of the match between worker and job, an understanding and acceptance of the learner's abilities, and an unhesitating commitment to refine training strategies to ensure efficient learning." Besides providing the many details necessary to create an effective supported employment program, the authors provide challenge and inspiration: "We invite you . . . to make a difference in the life of at least one person with severe handicaps--offer someone that chance to work, and the opportunity to experience the dignity that can come from working."

**Supported Employment: A Community Implementation Guide**, G.T. Bellamy, L.E. Rhodes, D.M. Mank, and J.M. Albin, Paul H. Brookes Publishing Company, 1988. Parents, educators, and human service workers will find this book to be invaluable for its advice on implementing supported work programs and helping more people with disabilities join the working world. This book is a practical guide that outlines goals critical to successful programs, describes employment models, and offers practical suggestions for forming a planning group and developing a program proposal. The authors also offer several management tools and guide the reader through important management decisions such as staff training and quality control. The authors conclude, "Supported employment is an opportunity, not a mandate. How it affects the lives of persons with disabilities in a community largely depends on the efforts of concerned people in that community."

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