

# Futurity

July 1993

Minnesota Governor's Planning Council on Developmental Disabilities

## National Family Support Legislation Drafted

A group of interested persons and organizations have formulated "first draft," proposed legislation entitled, "Children with Disabilities Family Support Act." This draft has been introduced to the Coalition for Citizens with Disabilities, and national advocacy organizations are considering endorsement. As stated by Allan Bergman in the *Family Support Bulletin* (Winter 1992/93), United Cerebral Palsy Associations, "It is now time for the United States Congress and the Clinton Administration to declare in substantive legislation that this country truly values families of children with disabilities, whatever the diagnostic label, and will financially support such families in order to strengthen the family's role as primary caregiver."

Along with several policies stated in the draft, the following examples could serve as "findings" in the proposed legislation:

- Families are the greatest natural resource available to their children and are the major providers of support, care, training and meeting other needs of their children living at home who require long-term care because of disability or chronic illness.
- It is in the best interest of the Country to preserve, strengthen, and maintain the family unit.
- Supporting families in their effort to care for the child at home is more efficient, cost-effective and humane than maintaining children with disabilities or with chronic illness in institutional settings or other out-of-home settings.
- It is a priority of Congress to assist States to plan and develop a comprehensive, statewide interagency policy to provide the services necessary, desirable and appropriate to support families throughout the states in keeping their children with disabilities or with chronic illness at home.

The purposes of the legislation would be to: a) enable families of children with disabilities to love, nurture, and enjoy their children in their homes; b) enhance the quality of family life; c) improve the availability and coordination of and access to an array of community services and supports to families; d) allow families to control the types of supports, services and goods made available to them; e) promote support, strengthen and preserve families; g) cover some of the special costs of caring for a child with a disability, preventing out-of-home placements, and returning children to family homes; h) assure availability of individually family-driven supports at the local/regional level; i) make available education and training for families to become knowledgeable and informed decision makers and advocates for their children; and j) recognize families as the primary persons responsible for ensuring the quality of family supports. "Family Support" is defined as: "goods and services needed by families to raise their child with a disability or chronic illness in the family home and to enjoy a quality of life comparable to other community members."

Several principles are specified, one of which reads, "All children, regardless of the type or severity of their disabilities, belong with and do best with families."

Family Support continued on page two

## Governor Appoints New Members to Planning Council

Governor Arne Carlson has recently appointed several new members to serve three-year terms on the Governor's Planning Council on Developmental Disabilities:

Patricia Ann Burns, Grand Rapids;  
William L. Everett, Minneapolis;  
Mary L. Golike, Apple Valley;  
Norena A. Hale, Ph.D., St. Paul;  
Stephen Harner, M.D. Rochester;  
Thomas Gerald (Jerry) Hayes, Excelsior;  
Andrew Hommerding, St. Cloud;  
Karol Johnson, Chanhassen;  
Debra G. Niedfeldt, Rochester; and  
Jerry Pouliot, St. Cloud.

Reappointments included: Karen Gorr, Gaylord; Anne Henry, Minneapolis; and Donna Petersen, Sc.D., Minneapolis. Twenty-seven people (service providers and non-service providers) serve on the Council.

The Minnesota Governor's Planning Council on Developmental Disabilities is responsible for supervising the design and implementation of a state plan. The Council provides systems advocacy by influencing policies which affect people with developmental disabilities and their families. The Council meets on the first Wednesday of even numbered months at the Earle Brown Center, University of Minnesota--St. Paul Campus. Copies of the *Three-Year Plan: Interdependence, Inclusion, Contribution* and a listing of other Council publications are available, call: 612/296-4018 (voice only); or 612/296-9962 (TDD).

## Inside This Issue...

*DD Council Allocates Funds*  
*U.S. Court Upholds Inclusion*  
*in Schools*  
*Assistive Technology RFP*

## Community Social Services Plans Underway

This is the year that counties will be developing their biennial Community Social Services Act (CSSA) plans. The CSSA requires that counties develop a means for citizen input to be included in the planning and budgeting process for human service programs.

Community Social Service plans include services such as day habilitation and training, case management, supported employment, semi-independent living programs and other services that counties provide for people with developmental disabilities and their families.

Your participation is critical. Watch for announcements in your local media and/or contact your county social service/human service agency to find out how you can provide input.

## Family Support Syndicate Created

The Human Services Research Institute (HSRI) recently organized "The Family Support Syndicate." The Syndicate is an information sharing network that provides family support groups nationwide with an avenue for exchanging ideas, concerns, and materials on current issues affecting individuals with disabilities and their families. A range of topics/issues will be addressed, such as: defining family support, identifying exemplary practices, educating policy makers, financing supports to families, and promoting legislative action. To find out more about the Syndicate, contact: Kerri Melda, Human Services Research Institute, 525 Glen Creek Road NW (k#230), Salem, Oregon. 503/362-5682.

## 'Family Voices' for Health Care Reform

Family Voices is a new national coalition of families and professionals speaking on behalf of children with special health needs. The coalition supports families as the core of any health care system; universal access; flexibility; comprehensive, coordinated, community-based care; family-professional partnerships; cost effectiveness; and quality assurance. For more information, write Family Voices, P.O. Box 769, Algodones, NM 87001.

## Council Allocates FFY 1994 Funds

On June 2, 1993, the Minnesota Governor's Planning Council on Developmental Disabilities approved an allocation of \$647,778 for projects in federal fiscal year (FFY) 1994. These allocations will assist the Council to implement its priority of **Leadership for Empowerment**. The allocations will be used for the following projects:

- **Youth Leadership**--The Metro YMCA will expand its in-school and after-school program and develop material to enable replication of this very successful program to other sites in Minnesota.
- **Partners in Policymaking**--This program was expanded to include two concurrent sessions, one to be held in the Twin Cities Metro area and one to be held in Greater Minnesota. In addition, a Partners Outreach Project will be designed to encourage greater participation of persons from minority communities.
- **Advanced Leadership**--A Negotiations Workshop and a three-day Summer Institute will be scheduled for graduates of Partners in Policymaking.
- **Mini-Grants**--A program of small grants (\$200 maximum) to persons who have completed either the Partners in Policymaking program or the Parents as Case Managers program to facilitate community organizing activities.
- **Conference/Training Grants**--A program of grants up to \$750 to organizations holding statewide conferences.
- **Person-Centered Planning**--A new program based on concepts pioneered by Ian Pumpian was approved. This program will train facilitators in the use of generic community resources toward full inclusion of persons with developmental disabilities.
- **Publications/Evaluation**--Funds were reserved to allow for printing and reprinting of Council publications and for evaluation of all projects.

For more information, contact: Minnesota Governor's Planning Council on Developmental Disabilities, 300 Centennial Office Building, 658 Cedar Street, St. Paul, MN 55155. 612/296-4018 (Voice); 612/296-9962 (TDD).

### Continued from page one

## Family Support

**Other principles include: focus on the whole family, flexibility, inclusion, family expertise, family contributions, and the importance of individual needs and aspirations.**

Funding would be intended to assist states to develop and implement family-driven, family-centered comprehensive initiatives for family support for families with a child with developmental disability. The proposed legislation outlines criteria for a state to be eligible to receive a grant in the first, second, and third years. Initially, states must: 1) designate the lead agency to administer the funds provided; 2) establish a State Family Support Policy Council, as appointed by the governor of the state, with two-thirds members representing families.

"Family Support Services" includes, but is not limited to, family services coordination, child and family-centered assistance including cash subsidies and vouchers, information and referral, educational materials, and emergency and outreach services.

The state Family Support policy initiative would offer both family support subsidy and family support goods and services. Twenty-three goods and services are listed in the proposed legislation, a few of which include: individualized planning and brokering, permanency/future planning, adaptive equipment and assistive technology, respite care, personal assistance services, integrated day care or child care, and family education/training services.

"Now is the time for families to communicate with their U.S. Senators and Representatives to let them know of their needs," Allan Bergman said.

## UCPA Plus Radisson Hotels Equals: *RESPITALITY*

United Cerebral Palsy Associations, Inc. and Radisson Hotels International have teamed up to give a break to parents of children who have cerebral palsy or a similar disability. Radisson Hotels offer parents a weekend away while respite care providers care for their children at home. "They love just being able to relax and renew a commitment between husband and wife," said Jo Ann Erbes, executive director of United Cerebral Palsy of Minnesota, Inc.

Respitality began in the Twin Cities two years ago. More than 100 families have benefitted from the program, and approximately 100 more are on a waiting list. To be eligible for respitality, family income and/or noted financial obligations which limit the opportunity for out of home entertainment are considered. Priority is given to those with cerebral palsy, who are between the ages of one year and 21 years of age, and are living at home.

United Cerebral Palsy Association and Radisson Hotels International started the program as a pilot project several year ago, and respitality is now nationwide. The company's goal is to provide one weekend per hotel per month. In Minnesota, five of the Twin Cities Radisson Hotels are participating, some committing more than one weekend per month.

While Radisson provides a room for the parents, the United Cerebral Palsy of Minnesota provides parents with a grant to pay for a care provider for their children at home.

For more information, contact: United Cerebral Palsy of Minnesota, 1821 University Avenue (#233-S), St. Paul, MN 55104. 612/646-7588, or 1-800-328-4827, Ext. 1437, toll-free.

## Publications

*No Pity: People with Disabilities Forging a New Civil Rights Movement*, Joseph P. Shapiro. New York, New York: Times Books/Random House, 1993. While working as Associate Editor (recently promoted to Senior Editor) for *U.S. News and World Report*, Joe Shapiro received the Alicia Patterson Fellowship to conduct an in-depth study of the issues in the lives of people with disabilities. *No Pity* represents the culmination of his travels and interviews across the country. Shapiro observed that the disability movement is far different than other comparable human rights movements. It has no one leader or organization that can claim to speak for all people with disabilities, and because of this it has gone largely unnoticed by nondisabled people. "But by its acceptance of differences, the campaign for disability rights has forged a powerful coalition of millions of people with disabilities, their families, and those who work with them," said Shapiro. "The disability movement is a mosaic movement for the 1990s. Diversity is its central characteristic."

Price: \$25.00, U.S.A.; \$32.50, Canada; plus 6% shipping and handling. Payable to: Random House Order Dept., 400 Hahn Road, Westminster, MD 21157. 1-800-733-3000, toll-free.

*Together We Can: A Guide for Crafting a Profamily System of Education and Human Services*, A. I. Melaville, M. J. Blank, and G. Asayesh, U.S. Department of Education and U.S. Department of Health and Human Services, April 1993. *Together We Can* offers a guide for communities interested in creating a profamily system of integrated services to address the complicated problems children and families face in today's society. Applicable to both urban and rural communities, this guide provides a process for fundamentally restructuring services and service delivery within and among child- and family-serving agencies: 1) outlining a vision for change; 2) realizing the vision (a five-stage process); and 3) profiles of communities moving toward their vision. Appendices include: checklists to measure collaborative progress, directory of contacts and resources, and an extensive bibliography. Purchase from: U.S. Government Printing Office, Superintendent of Documents, Mail Stop: SSOP, Washington, DC 20402-9328. (Indicate ISBN Number: 0-16-041721-X.)

## Request for Proposals on Assistive Technology Regional Grant Workshops Scheduled

The STAR Program of the Governor's Advisory Council on Technology for People with Disabilities is inviting submission of proposals by public and private organizations for the purpose of establishing or expanding programs providing technology-related assistance to people with disabilities in Minnesota. Funding is awarded in two categories:

1) Assistive Technology Resources (range: \$5,000-\$25,000); and 2) Mobile Delivery Programs (range: \$40,000-\$100,000).

Deadline for submission of proposals is October 1, 1993.

Technical assistance for potential applicants is available through workshops and individual consultation at the following locations:

August 2, 1993--Moorhead Madison Inn, Moorhead

August 9, 1993--Eveleth Holiday Inn, Eveleth

August 16, 1993--Marshall Best Western, Marshall

August 20, 1993--St. Paul Sheraton Midway, St. Paul

August 23, 1993--Rochester Community College, Rochester.

All workshops are scheduled from 9:00 a.m. to 12:00 noon. Pre-registration is required.

For grant applications and workshop registration, contact: STAR Program, 300 Centennial Building, 658 Cedar Street, St. Paul, MN 55155. 612/296-2771 (voice); 612/296-9962 (TDD); 612/297-7200 (FAX).

## Mark Your Calendar

September 26-29, 1993

The 11th Annual National Home and Community-Based Services Conference, "Living Everyday Lives," will be held at the Trade Winds Hotel, St. Petersburg, Florida. Contact: Center for Professional Development and Public Service, Florida State Conference Center, R-55, Florida State University, Tallahassee, FL 32306-2027.

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*I know many people who are paralyzed from the neck up-- those who can't think and who are unable to accept the differences of others. These may be the ones with the greatest disabilities.*

Ed Roberts, 1993  
World Institute on Disability

## Lending Library

The following resources are available on loan; publications for three weeks; videotapes (VHS 1/2" cassette) for two weeks. The only cost to the borrower is the return postage. See return address and telephone numbers below.

*It's Michael's Money* (videotape, 45 minutes). Innovative training for representative payees, describes responsibilities for administering funds received from Supplemental Security Income, Social Security Administration, and the value of individual choices.

*Don't Be Surprised* (videotape, 20 minutes), National Association for Down Syndrome. Panel of self-advocates share their personal experiences.

*Kids Belong Together* (videotape, 30 minutes), People First Association of Lethbridge, Alberta, Canada. Through cohesive circles of friends, communities become a place for everyone. Elementary school students, classmates, teachers, and parents learn the importance of having and sharing their dreams about their futures.

### Council Publications on Audiocassettes:

- 1) *Futurity* (monthly newsletter);
- 2) *Minnesotans Speak Out!, Summary of Town Meetings Held Throughout Minnesota* (November 1992); and
- 3) *Shifting Patterns* (October 1992). Contact Minnesota Governor's Planning Council on Developmental Disabilities, as indicated on return address, below.

## U.S. Court Upholds Inclusive Classrooms

On May 28, 1993, the United States Court of Appeals for the Third Circuit upheld the right of children with disabilities to be included in regular classes with non-disabled children. In the case of *Rafael Oberti v. Board of Education of Clementon, New Jersey*, the Appeals Court affirmed a federal district court ruling that eight year old Rafael Oberti, a child with Down Syndrome, be provided an inclusive education in regular class in his home school.

U.S. Circuit Court Judge Edward R. Becker, wrote, "We construe the Individuals with Disabilities Education Act (IDEA), P.L. 101-476, mainstream requirement to prohibit a school from placing a child with disabilities outside of a regular classroom if educating the child in the regular classroom, with supplementary aids and support services, can be achieved satisfactorily. In addition, if placement outside of a regular classroom is necessary for the child to receive educational benefit, the school may still be violating IDEA if it has not made sufficient efforts to include the child in school programs with non-disabled children whenever possible."

The Court of Appeals made it clear that the presumption in favor of inclusion in regular classes means that the burden of proving compliance with IDEA's mainstreaming requirement is on the school district, not the parents. As Judge Becker wrote: "The Act's strong presumption in favor of mainstreaming . . . would be turned on its head if parents had to prove that their child was worthy of being included, rather than the school district having to justify a decision to exclude the child from the regular classroom." In all cases, the Court ruled, children with disabilities must be included in school programs with non-disabled children whenever possible.

Copies of the full opinion are available for \$5.00 to cover the cost of copying. Contact: Rosemary Lavin, Public Interest Law Center of Philadelphia, 125 South 9th Street, Suite 700, Philadelphia, PA 19107. 215/627-7100.

*"My son has multiple abilities and a few challenges."*  
A Creative, Positive Thinking Mother

## Futurity

### DEPARTMENT OF ADMINISTRATION

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# Futurity

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Minnesota Governor's Planning Council on Developmental Disabilities

## Colorado Surveys Quality of Life Instruments

Last year, Colorado re-designed an instrument to be used in an ongoing longitudinal survey of people with developmental disabilities. The project called, "COPAR," Colorado Program Assessment and Review, begun in 1986, needed revision to adequately address the Division's new mission statement. Therefore, the Division of Developmental Disabilities of the Colorado Department of Institutions contracted with Allen, Shea, & Associates of California to look at the state-of-the-art and best practices throughout the country.

Seventy-two measurement instruments were reviewed and compared against the values stated in the Division's new mission statement, including: friendship and belonging; self-esteem, competencies and talents, decision-making, community inclusion, and satisfaction. The following conclusions were drawn about the existing tools:

- Most tools have been developed as a method of evaluating services or reviewing compliance with quality assurance standards.
- Most tools are concerned with *lifestyle*, that is, observable life patterns (what people do, where they do it, and when), *environments* (what places look like) and *observable behavioral characteristics* (do people have an opportunity for choice, how do they spend their free-time).
- Some tools include *life quality measures* (personal and subjective measures of how things are going) along with *lifestyle* measures.
- Few measures focus solely on *life quality*.
- About one-third include an interview with the person with a disability.
- Most have not considered alternative methods of data collection for persons who have limited communication skills.
- Most have not been studied to determine reliability or validity.
- Most have not been standardized, nor do they offer interpretive guidelines.

As a next step in the process of developing a model quality assurance system, key informants were contacted about their views. A number of issues were identified:

**What Should Be Measured?** Greater respect must be given to the likes, dislikes, hopes, dreams and preferences of *individuals*. For example, person-centered planning and support are elements of a paradigm shift away from the traditional medical/developmental/readiness model. *Quality of life* must be measured by a balance of both objective and subjective methods.

**How Can Quality Be Measured/Reported?** In view of time/energy (efficiency), keep 'key questions and observations' to an absolute minimum, which are individualized as much as possible.

Quality Assurance continued on page two

## On Commitment

*Until one is committed,  
there is hesitancy,  
the chance to draw back...  
Always ineffectiveness.*

*Concerning all acts of initiative  
and creation  
there is one elementary truth,  
the ignorance of which kills  
countless ideas and splendid plans:  
that the moment  
one definitely commits oneself,  
then providence moves too.*

*All sorts of things occur  
that would never otherwise  
have occurred.*

*A whole stream of events  
issues from the decision,  
raising in one's favor  
all manner of unforeseen incidents  
and meetings and material assistance  
which no one would have  
dreamt would come one's way.*

*I have learned a deep respect  
for one of Goethe's couplets--*

*"Whatever you can do  
or dream you can, begin it.  
Boldness has genius,  
power, and magic in it."*

W.H. Murray

[Source: *The Whole Community Catalogue*, David Wetherow (Ed.), Communitas, Inc., 1992, p 61.]

*Inside This Issue...*

- *Minnesota Relay Service  
Certified by FCC*
- *Disability and Aging  
Conference—  
September 30, 1993*

## Call for Papers: Parent-to-Parent Conference April 29-May 2, 1994

**Wanted:** presenters who will energize and educate people about advocacy, family support programs, and legislative action at the 1994 International Parent-to-Parent Conference, to be held in Asheville, North Carolina. The Conference will be hosted by the Family Support Network of North Carolina. Presentations will be made in workshop or poster session formats. Proposals must be submitted by September 6, 1993. To receive a preliminary brochure and application, contact: Holly Riddle or Bebie Cole, North Carolina Council on Developmental Disabilities, 919/733-6566.

## Information About The Arc Provided in Spanish

The Arc (formerly called Association for Retarded Citizens-United States) recently published a fact sheet in Spanish that describes the organization and how to become involved. Contact: The Arc, National Office, P.O. Box 1047, Arlington, TX 76004. 817/261-6003 (voice); 817/277-0553 (TDD).

## MN-Care Information Line

Find out about Minnesota's health insurance coverage for individuals and families who do not have coverage and who qualify. CALL: 1-800-657-3672 for recorded information.

## Greater Minneapolis Day Care Association Has Resources for Children with Special Needs

Serving Hennepin County, the Greater Minneapolis Day Care Association can now provide the following resources and services to families and day care providers: 1) A booklet to help choose child care arrangements, *Child Care for Children with Special Needs*; 2) Individualized planning; 3) Screening and referrals. For more information, contact: Jean McGuire or Beth Koskie, GMDCA, 1628 Elliot Avenue South, Minneapolis, MN 55404. 612/341-1177 (voice); 612/341-2066 (TDD); 612/341-4356 (FAX);

## Minnesota Relay Service Certified

Governor Arne Carlson recently announced that the Federal Communications Commission (FCC) has granted a five-year certification to the Minnesota Relay Service which offers improved services to relay users. The FCC is in the process of certifying relay systems throughout the country under the authority delegated to it by the Americans with Disabilities Act of 1990. This service assures that people with speech, hearing, or vision impairments, can communicate directly with others using standard telephone equipment. Calls are facilitated by a communications assistant. As required by law, both "voice carryover" and "hearing carryover" services are provided by the relay assistant.

"Minnesota was the fourth state in the United States to establish a relay service in 1989," said Bill Lamson, Program Administrator of the Telecommunications Access for Communication Impaired Persons Board (TACIP). The Minnesota Relay Service is operated by the Deafness Education and Advocacy Foundation (DEAF) under contract with TACIP. These services are funded by a monthly surcharge on customer telephone lines; all Minnesota telephone companies collect the surcharge. For more information, contact by voice or TDD: 612/297-5353 (Metro Area); 1/800-627-3529.

## Continued from page one

### Quality Assurance

**Why Measure?** The primary reason is monitoring--looking at the relationship between programs and services, and the quality of people's lives. Other reasons are curiosity, fine tuning, and choosing one program/service design over another.

**How Do Quality-of-life Measurements Fit Into A Quality Assurance System?** It appears that the term *quality of life* is used to mean at least three different things: life's *timbre*, *life style*, and life's *value*. It may be helpful to separate them and use the term quality of life for only one of them. As suggested in *Rehab Brief* (Vol. XI, No. 1):

- **Life Quality:** the timbre of a life as experienced subjectively; one's feelings about/evaluation of one's own life; almost congruous with "life satisfactions: but allowing for individuals to rate quality of life high in spite of pain or dissatisfaction when they see it as leading toward growth.
- **Lifestyle:** the constellation of one's observable behavioral patterns and characteristic surroundings--places, possessions and people; this one is not a valiative dimension but just the facts of what you do, how, and under what circumstances.
- **Life Value:** the evaluation of one's life by another person; how worthy one is considered to be; how valuable are one's productions/contributions; how costly one is to others--monetarily, psychologically, or in other ways. Life value may be judged contemporaneously or historically.

For more information about this study of quality assurance measurements, contact: Allen, Shea, and Associates, 1040 Main Street, Suite 200B, Napa, CA 94559. 707/258-2356. To find out more information about the Colorado COPAR Project, please contact: Judy Ruth, Division of Developmental Disabilities, 3824 West Princeton Circle, Denver, CO 80236. 303/762-4578.

[Source: *Explorations*, Allen, Shea, and Associates, Summer 1992.]

## Minnesota Prevention Resource Center Has Something for Everyone

The Minnesota Prevention Resource Center (MPRC) is a statewide clearing-house for alcohol and other drug information. It is a project of the Minnesota Institute of Public Health, funded by the Chemical Dependency Program Division, Minnesota Department of Human Services. Services include: audiovisual loans, reference library, public education materials, and community assistance and public speaking. MPRC also publishes *IMPACT*, a free quarterly newsletter about chemical health in Minnesota. For a free *MPRC CATALOGUE, 1993*, contact the Anoka Office listed below. A new publication was recently released: *Idea Sampler to Promote Awareness of Fetal Alcohol Syndrome and Effects*.

There are two offices that perform different services: 1) For audiovisual loans, educational materials and programs, contact the Anoka Office: 2829 Verdale Avenue, Anoka, MN 55303; 612/427-5310, or 1-800-247-1303, toll-free; 2) For reference library, speakers, and consultants, contact the St. Paul Office: 417 University Avenue, St. Paul, Mn 55103-1995; 612/224-5121; or, 1-800-223-5833, toll-free.

## Learning and Fun Resources for Children

The Oppenheim Toy Portfolio, published quarterly, is an informative booklet containing practical information about toys, books, audio and video tapes for children of all ages. It includes a section of "regular" toys that can easily be used with and by children with disabilities, often with a suggestion for use or adaptation. The toys are generally available in regular toy stores, although some are found in specialty shops or catalogues. Wherever possible, a phone number is listed to help locate the selection.

Products that are listed in the Portfolio are selected by a team of experts in child development, children's literature, and education. They are then sent home with children for "real life" judging.

The Oppenheim Toy Portfolio, Inc. is not affiliated with toy manufacturers, catalogues, or stores. The publisher of the booklet is an educator and editor at the Bank Street College of Education in New York. Price: \$12.00/year, payable to The Oppenheim Toy Portfolio, 40 East 9th Street, New York, NY 10003. 212/598-0502.

## Publications

*Her shoes are brown and other stories*  
and

*Jumping the gap: more stories and ideas*

Both books are by Chris Hicks, Barbara Leavitt, and Diane Peacock, who collected stories from people across Southern Ontario, people who shared their challenges and triumphs. *Her shoes are brown* celebrates journeys that include all of us. These stories touch our hearts with their beauty, and our minds with what they can teach us. *Jumping the gap* tells about the gap between philosophy and action; action toward supporting each other so that people can truly contribute to their communities. The two books confront the nitty gritty about the realities of doing "connecting" and "community" work. Price: \$15.00 per set, plus \$3.50 (U.S. dollars) for shipping and handling, payable to Tillsonburg and District Association for Community Living (T.D.A.C.L.). Mail to: Community Involvement Council, Box 344, Tillsonburg, Ontario, Canada N4G 4H8.

## Events

**September 15 & 16, 1993**

"Opening Doors," the 1993 Minnesota Semi-Independent Living Services (SILS) Conference, will be held at the Holiday Inn in St. Cloud. Contact: Laura Lund, 612/870-0383; or Sharon Polcher 218/263-8911.

**September 23, 1993** (Short version--6:30 p.m. to 9:30 p.m.)

**September 24, 1993** (Longer version--9:00 a.m. to 3:00 p.m.)

A workshop on Supplemental Security Income (SSI) will be presented by Dan Scarborough, editor of *Disability Benefits in Brief*, at Courage Center, Golden Valley. Fee: free to family members and people with disabilities, and \$15.00 for professionals. Contact: Lyn Cramer or Cathleen Urbain at PACER Center, 612/827-2966, voice/TDD.

**October 3-6, 1993**

"Toward Whole Communities" is the First Annual Autumn Institute sponsored by The New Hampshire University Affiliated Program that will be held at the New England Center, Durham, NH. Keynoters will address community inclusion issues and strategies, including Jan Nisbet, George Flynn, and Bob Williams. Contact: First Autumn Institute, New England Center, Kellogg Program Office, 15 Stafford Avenue, Durham, NH 03824-3560. 603/862-0245 (voice); 603/862-4320 (TDD).

**October 5, 1993** (4:30 p.m.-6:30 p.m.)

"Celebrate Success," organized by a coalition of 30 agencies representing people with disabilities, will be held at the Mall of America. Awards will be presented to individuals in the areas of building design, accessibility, employment, and outdoor environment. Nominations must be submitted before September 1, 1993. Contact: Jane Borochoff, 612/938-5511; or Cathy Milota, 612/827-2966.

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*We keep thinking about evaluation as autopsies instead of smoke detectors. You have to start the evaluation process early so that learning starts from day one.*

Susan Philliber  
Philliber Research Associates

## Lending Library

The following resources are available on loan from the Minnesota Governor's Planning Council; publications for three weeks; videotapes (VHS 1/2" cassette) for two weeks. The only cost to the borrower is the return postage.

See return address and telephone numbers below.

***Tools of the Trade: A Hands-On Program to Train Supported Employment Personnel***, D. Lavin, et al., Minneapolis: Rise, Inc., 1990. This seven-book series provides a comprehensive training program for personnel in supported employment: 1) manager's guide; 2) introduction to supported employment; 3) career planning and job development; 4) training and support; 5) inclusion; 6) case management; and 7) survival skills. [Note, this may be purchased from: Rise, Inc., 8406 Sunset Road, NE, Spring Lake Park, MN 55432. 612/786-8334.]

***How to Organize an Effective Parent/Advocacy Group and Move Bureaucracies***, Family Resource Center on Disabilities, Revised in 1993. First published by parents in 1971, many groups have benefitted from this guide. Knowledge is power. This guide can help parents get organized, and can revive and inspire established groups. [Note, this item may be purchased for \$10.00, plus \$2.00 postage, payable to: Family Resource Center on Disabilities, 20 East Jackson Blvd. (#900), Chicago, IL 60604. 312/939-3513.]

***Publicity Kit: Prevention of Fetal Alcohol Syndrome (FAS/FAE)***. This is a notebook containing a collection of publications and ideas on how to organize public awareness campaigns and provide training about FAS/FAE, which are entirely preventable.

## "At the Crossroads" Conference on Disability and Aging Scheduled

On Thursday, September 30, 1993, Courage Center and Opportunity Workshop will be sponsoring a regional conference on "At the Crossroads: Disability and Aging" at the Radisson Hotel in Minnetonka. Deborah L. McFadden, former Commissioner of the Administration on Developmental Disabilities will be the keynote speaker.

The conference will offer time to attend two workshops (out of eight choices), led by experts in the fields of disability and gerontology. Closing session, "The Spirit of Aging," will be presented by Carol Bly, Minnesota author, poet, and educator. Reception will follow the closing session.

Co-sponsors include: Minnesota Governor's Planning Council on Developmental Disabilities, Minnesota Board on Aging, Minnesota State Council on Disability, Minnesota Gerontological Society, and the American Association on Mental Retardation-Minnesota Chapter.

Fee: \$75.00, which includes continental breakfast, lunch, breakout sessions, and materials. For more information, contact: Ann Roscoe, Courage Center, 612/520-0210 (voice) 612/520-0410 (TDD); or Cindy Tarshish, Opportunity Workshop, 612/938-5511 (voice), 612/930-4293 (TDD).

## Council Publications in Alternative Formats

Please tell your friends and colleagues who do not read print that several publications by the Minnesota Governor's Planning Council are now available in other formats, such as:

- 1) ***Futurity***, on audio cassette and is available through DRAGnet (an electronic bulletin board);
- 2) ***Minnesotans Speak Out!***, ***Summary of Town Meetings***, audio cassette; and
- 3) ***Shifting Patterns***, publication in Braille and on audio cassette; and videotape with closed captions.

Contact Minnesota Governor's Planning Council on Developmental Disabilities. See return address and telephones, below.

## *Futurity*

### DEPARTMENT OF ADMINISTRATION

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# Futurity

September 1993

Minnesota Governor's Planning Council on Developmental Disabilities

## Bob Williams Appointed ADD Commissioner

On July 26, 1993, exactly three years after the signing of the Americans with Disabilities Act, Health and Human Services Secretary Donna E. Shalala named Bob Williams as the Commissioner of the Administration on Developmental Disabilities.

Williams, age 36, has been a leader in the disability rights movement, working as a policy associate with the United Cerebral Palsy Associations, Inc. He has also co-chaired the Task Force on Rights and Personal Assistance Services of the Consortium for Citizens with Disabilities. Prior to his service with the UCPA, Williams was deputy director of the Pratt Monitoring Program of the D.C. Association for Retarded Citizens. He was one of three U.S. District Court-appointed monitors charged with monitoring the closing of Forest Haven, the District's institution for people with developmental disabilities, and the development of community support services for those who lived there.

Williams has also served as president of Hear Our Voices, an organization for people who rely on augmentative communication devices; and vice president of the Association for Persons with Severe Handicaps (TASH).

"Bob is a nationally recognized expert on the best ways to create supports for people with multiple disabilities to live, work, and play in their communities," Shalala said. "He believes in community--not just as a place to live, but as a complete way of life, for all of us."

Williams received a bachelor's degree in urban affairs from George Washington University. He has cerebral palsy, and joins the 1,700 federal employees in Washington, D.C. who have severe disabilities.

**Note from the Editor:** Bob Williams also authored his own book of poetry in 1989, *In a Struggling Voice*, published by Modern Industries, Fitzgerald, Georgia (telephone: 912/423-9313).

## 1993 Cost of Care Rate at RTCs Announced

The Minnesota Department of Human Services (DHS) recently announced the daily rates for the Cost of Care in Regional Treatment Centers (RTCs) for persons with mental retardation and related conditions. Effective July 1, 1993, the daily charge for care at each of the seven RTCs will be \$310 per person. This would amount to \$113,150 per person each year.

DHS calculates interim charges on a per diem basis for each fiscal year (July 1 to June 30) by dividing the sum of all anticipated costs by the projected resident days. The per diem rate last year for persons with mental retardation and related conditions was \$287.70, or \$105,011.

Care Rates Continued on page two



Ron Kaliszewski (left) receives recognition from Council member Byron Johnson, M.D.

## Ron Kaliszewski Retires

After 29 years of state employment, Ron Kaliszewski left the staff of the Minnesota Governor's Planning Council on Developmental Disabilities. Ron was contract manager for the Council during the past 12 years. Previously, he worked with the Office of Local and Urban Affairs, where he was instrumental in the establishment of the Regional Development Commissions.

Ron has played an important part of the Council's agenda for change, influencing the quality of grants and contracts relating to: supported employment, Partners in Policymaking, parents as case managers, case management practices, voucher programs, youth leadership, and personal futures planning.

### Inside This Issue...

- Centralization of Metro Mobility
- Sue Swenson Testifies Before Congressional Committee

## Metro Mobility Centralizes Services—October 2, 1993

Customers who use Metro Mobility, a service of the Regional Transit Board, will be receiving streamlined services through a newly established Metro Mobility Service Center. Starting October 2, 1993, the Service Center will coordinate all reservations, scheduling, and dispatching of rides. It will also coordinate trips between the county providers and the service areas. New vehicles are equipped with wheelchair lifts.

To make reservations for any ride from within the Metro Mobility Service area, call 612/221-1928. Persons living outside the service area must call their county service provider. Those who are not currently certified and would like to use Metro Mobility, call 612/221-1932 after October 1, 1993. For additional information, call Linda Rother, Metro Mobility Service Center, 245 East 6th Street, Suite 200, St. Paul, MN 55101. 612/221-1932.

*"Black people fought for the right to ride in the front of the bus. We're fighting for the right to get on the bus."*

**Mark Johnson, ADAPT**  
Atlanta, Georgia activist

## Care Rates continued from page one

Two years ago (in 1991), the per diem rate was "\$271.45, or \$99,079 per year."

As of June 1993, the total population of persons with mental retardation and related conditions residing in all seven RTCs was 862. The total number being served in June 1992 was 1,033, indicating a reduction of 171 persons who were placed into public and private community residences.

For more information, contact Larry Houff, Reimbursement Division, Department of Human Services, 2nd Floor, Human Services Building, 444 Lafayette Rad, St. Paul, MN 55155-3824. 612/296-4889.

## Voice from the Kindergarten Table by Jeff Tate

I was sitting there, ya know, right where I always sit next to Eve and Josh and George Sapito (he has hair all the way down his back ya know). We all sit together at the same big table, all of us together.

Stefen sat at our table for awhile. I mean he was with us . . . all of us—Me, Eva, Josh, George Sapito (with the long hair) and uh, Stefen, who was a cool spitter. We was always together. Our kindergarten table.

But ya know what? One day Stefen wasn't there anymore. He was just gone. I asked Mrs. Gillooly, "Where's my friend Stefen? Is he sick?"

"Yeah, where is he?" asked Eva and Josh and George Sapito (with the long hair down his back).

"Well," said Mrs. Gillooly, "Stefen does not belong here. He is too different and needs special help. He needs his own classroom with others who need help. Others like him."

"Oh," I said, "aren't we going to have a going away party for Stefen like we did for Marsha Materinski when she moved to San Francisco?"

"No," said Mrs. Gillooly.

"This place where Stefen went," I asked, "is it like special because he's dead or something?"

"No," said Mrs. Gillooly.

"Will I be different soon and have to go to this special place?"

"I don't think so," said Mrs. Gillooly.

Ya know, I thought about all this stuff and I guess my friend Stefen must of done some real bad stuff to go to this special place. Maybe he went there cause he didn't drink his milk last week at lunch. Yep. I bet that's it!

I told him to drink it. I told him to!

I told Eva and Josh and George about the milk. They said, "Yes, it must have been the milk that Stefen did not drink that made him go away to a special place."

We always drink our milk now.

And so far, me and Eva and Josh and George (with the long hair down his back) are still at our kindergarten table all the time.

I will always drink my milk, always. I promise.

Abridged from *Safety Net*, Summer 1993, with permission from the author--Jeff Tate, who is Chairperson for the Capital Area SAFE (Schools Are For Everyone) Chapter, Austin, Texas, and is employed by the Arc Texas.

## Minimizing the Jargon Trap

One of the things that can make people with disabilities appear "different" is the language used by service providers at a worksite. For example, if you tell a supervisor "I'm picking up Joe after work for his ISP meeting," the supervisor could think Joe is being abducted by aliens from outer space. Why not say, "Joe and I are getting together after work to talk about some of his plans?" Other terms might include:

### HUMAN SERVICE JARGON

- Gross motor
- Fine motor
- Case Manager
- Eight-bed residence
- Dually diagnosed
- Natural support

### REAL LIFE MEANING

- Dirty engine
- Mercedes Benz
- Beer distributor
- A small hotel
- Very sick; confirmed by second opinion
- Comfortable underwear

Add to the list. These ideas come from: David Hagner and Dale Dileo (1993), *Working Together: Workplace Culture, Supported Employment, and Persons with Disabilities*, Brookline Books, p. 199.

# Radical and Proud

by Sue Swenson

*Because I say that everyone should be included and that self-determination is possible for people with severe disabilities, some people have called me a radical.*

*If it is radical to be suspicious of the opinions of experts who want to tell me what is best for my family, then I am radical.*

*If it is radical to think my son should be in charge of his own life, then I am a radical.*

*Viewing experts with suspicion is an American tradition. Devotion to self-determination is an American tradition. Belief in the dignity and value of the individual is an American tradition. So perhaps I am a traditional American radical just moving on to 'the last great inclusion of American life.'*

Excerpt from testimony to the U.S. Senate Subcommittee on Disability Policy hearing regarding the reauthorization of the Developmental Disabilities Assistance and Bill of Rights Act, June 29, 1993. Sue Swenson is a graduate of Minnesota Partners in Policymaking. A complete copy of her testimony is available from the Minnesota Governor's Planning Council on Developmental Disabilities. See return address and phone numbers on page 4.

## Publications

***Making Friends: Using Recreation Activities to Promote Friendship Between Children With and Without Disabilities***, Linda A. Heyne, Stuart J. Schleien, and Leo H. McAvoy, University of Minnesota, 1993. Although friendships happen spontaneously, adults can provide many practical supports to encourage sustained relationships. This handbook is intended to assist community recreation staff, teachers, and parents in providing this support to elementary school age children. The following topics are explored: What do friendships mean for children? What inhibits friendships? How can friendships be encouraged in school and recreational settings? Available through the Lending Library, see page 4, or may be purchased for \$10.00, payable to University of Minnesota. Contact: Institute on Community Integration, University of Minnesota, 109 Pattee Hall, 150 Pillsbury Driver, SE, Minneapolis, MN 55455. 612/624-4512.

***Living in the State of Stuck: How Technology Impacts the Lives of People with Disabilities***, Marcia J. Scherer, Brookline Books, 1993. Funded by a grant from the National Science Foundation, Marcia Scherer studied assistive technology from the perspective of the people who use them. Assistive technology is radically changing the lives of persons with disabilities. Scherer agrees that the value of assistive devices is great, but she calls attention to the human dimensions--to help persons relate technology to their own lives, and understand their potential. **The psychological factors which enhance acceptance of a disability and use of the devices need more consideration by rehabilitation professionals, educators, employers, and parents.** Many personal stories are shared. For example, Brian, who received a spinal cord injury as a result of a motorcycle accident, aptly captured the excitement: "It's mind boggling when you think of the things that they're coming up with. There are so many advantages. [He paused, grinned, and added,] I mean, I'm glad I broke my neck in this century." This publication is available on loan from the Lending Library (see page 4), or may be purchased from Brookline Books, P.O. Box 1046, Cambridge, MA 02238. 617/868-0360.

## Events

### September 23-34, 1993

MAGIC, Minnesota Association for Guardianship and Conservatorship, an organization to explore substitute decision-making, will hold its fourth annual conference, "Incapacitated and Vulnerable Adults" at the St. Paul Hotel. Contact: MAGIC, P.O. Box 14246, St. Paul, MN 55114.

### September 30, 1993

"At the Crossroads," conference on disability and aging, will be held at Radisson Hotel in Minnetonka. Contact: Ann Roscoe, Courage Center, 612/520-0210 (voice) 612/520-0410 (TDD); or Cindy Tarshish, Opportunity Workshop, 612/938-5511 (voice), 612/930-4293 (TDD).

### October 5, 1993 (4:30 p.m.-6:30 p.m.)

"Celebrate Success," organized by a coalition of 30 agencies representing people with disabilities, will be held at the Mall of America. Awards will be presented to individuals in the areas of building design, accessibility, employment, and outdoor environment. Nominations must be submitted before September 1, 1993. Contact: Jane Borochoff, 612/938-5511; or Cathy Milota, 612/827-2966.

### October 21-23, 1993

Closing the Gap Conference, exploring microtechnology in special education and rehabilitation, will be held at the Radisson South Hotel and Hotel Sofitel, Minneapolis, MN. **Preconference workshops are scheduled October 19-20.** Contact: Closing the Gap, P.O. Box 68, Henderson, MN 56044. 612/248-3294.

### November 5, 1993

A national conference, "Older Adults with Developmental Disabilities and Older Caregivers," will be held at the Hartford Marriott Rocky Hill, East Hartford, Connecticut. Contact: Maggie Carr, Connecticut Council on Developmental Disabilities, 90 Pitkin Street, East Hartford, CT 06108. 203/725-3829 (voice); 203/725-3921 (TDD).

### November 22, 1993 (12:00 to 4:00 p.m.)

The eighth annual Job Success Fair, "Exploring Your Options," will be held at the Marriott Hotel, 2020 East 79th Street, Bloomington. Contact: Nancy Schuett, Disability Services, City of Bloomington, at 612/887-9604, Ext. 409, (voice); 612/887-9677 (TDD).

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## Lending Library

The following resources are available on loan from the Minnesota Governor's Planning Council; publications for three weeks; videotapes (VHS 1/2" cassette) for two weeks. The only cost to the borrower is the return postage. See return address and telephone numbers below.

***Making Friends: Using Recreation Activities to Promote Friendship Between Children With and Without Disabilities***, Linda A. Heyne, Stuart J. Schleien, and Leo H. McAvoy, University of Minnesota, 1993. See description under "publications" on page 3.

***Living in the State of Stuck: How Technology Impacts the Lives of People with Disabilities***. See description under "publications" on page 3.

***Friendships and Community Connections between People with and without Developmental Disabilities***, Angela Novak Amado (ED.), Paul H. Brooks Publishing Co., 1993. Three sections address: 1) dimensions of friendship; 2) stories of friendships; and 3) strategies for building friendships. See article to the right of this column.

## On Being a Friend

by Jane Wells

Being a part of Mary Ann's life has enriched my life immeasurably. I have learned important lessons about the nature of relationships and have come to appreciate more fully the gift of friendship. Friendship takes a great deal of time. It is not something that you can accomplish by taking a person on a community outing every Thursday from 4:00 p.m. to 6:00 p.m. It happens when people find themselves on the same journey. It deepens when the travelers come to depend on each other—to read the map, to know where the next gas station is, to take pictures to capture the memory. An important part of friendship is just wasting time together—remembering shared experiences, being tired from a hard day's work, watching the sunset, or listening to the evening traffic.

For Mary Ann, friendship happens in moments of everyday life. It means that someone is there to help you and to compliment you. It means that you can get angry at each other and say mean things and then be able to apologize and forgive. Friendship means that you share the conviction that the household cats are the cutest and funniest cats in the world. Friends stick up for each other and pray for each other and care for each other. Friends can say, "I love you," and not get embarrassed. Friends are there for you, even when you cannot be there for them.

Source: "Making It Up as We Go Along," *Friendships and Community Connections between People with and without Developmental Disabilities*, (1993) Angela Novak Amado (Ed.), Paul H. Brooks Publishing Company, pp. 206 & 211. Jane Wells is a consultant and trainer through Creative Community Options in White Bear Lake, Minnesota. This publication may be purchased from Paul H. Brooks Publishing Company, P.O. Box 10624, Baltimore, MD 21285-0624. 1/800/638-3775, toll-free.

*"I believe that friendships with people who have disabilities can provide an explosion of fresh values and directions which this confused, misdirected world needs now as never before."*

Robert Perske

*Circle of Friends (1988)*

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## Futurity

### DEPARTMENT OF ADMINISTRATION

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# Futurity

October 1993

Minnesota Governor's Planning Council on Developmental Disabilities

## **A Story of Empowerment: Changing the World, Together**

**by Sue Swenson**

The following article summarizes key statements from Sue Swenson's testimony to the Senate Subcommittee on Disability Policy Hearing Regarding Reauthorization of the Developmental Disabilities Assistance and Bill of Rights Act on June 29, 1993. As *Futurity* is going to press, Congress is still discussing and deciding upon the Act's reauthorization.

\* \* \* \*

I live in Minneapolis, Minnesota, with my husband Bill and our three sons: Will, who is 13; Charlie, who will be 11 in August; and Eric, who is 5. I was the third generation of my family to grow up in Red Wing, Minnesota, which is just down the road from Lake Wobegon. I went to college and graduate school at the University of Chicago. I thought my supportive family and good education made me ready to be a good parent. As it turned out, a program made possible by the Developmental Disabilities Act made more difference than anything else. I want to tell you my personal story of empowerment. Because of the DD Act there are many other people who have stories like mine to tell. I could try to give you numbers, but I couldn't dream of telling all the stories. I think the personal impacts of empowerment are greater than the numbers might show.

Ten years ago when Charlie was nine months old, his pediatrician first acknowledged that he had severe and multiple disabilities. I was pretty sure that the bottom had dropped out of my life. No one I knew had any ideas that could help me deal with the reality of raising a son who probably would not walk or talk, and who probably couldn't see very well, either. My experiences were typical of the times: I knew very few people with disabilities and no people with severe disabilities. Over the years I collected the usual images from the movies like "The Miracle Worker," which taught me that good strong people can fix anything if only they never give up. If you add to that a few quick channel changes through the ridiculous telethons and a few passing glances at those ads offering a "loving environment for your handicapped loved one" in the back of magazines and some men panhandling from wheelchairs in downtown Chicago, you have about exhausted my whole experience with disability before my son was diagnosed.

I wish I could say we faced the challenge of our son's disability heroically, but we didn't. I spent whole weeks crying. We struggled. We couldn't find anybody willing to care for a baby with disabilities, so one of us had to be home all the time. As time went on and Charlie got bigger, we avoided taking our boys out, even to the park, because we couldn't cope with all the prayers, pity, stares, and outright hostility we encountered. We worked very hard on the therapies, silently hoping that Charlie would "get better" so we could go back to the real world. We were pretty grim, even for Scandinavians. I remember that time as one long black-and-white Bergman movie.

**Changing the World** continued on page two

## ***Follow Your Bliss***

*This, I believe is the great Western truth: that each of us is a completely unique creature and that, if we are ever to give any gift to the world, it will have to come out of our own experience and fulfillment of our own potentialities, not someone else's.*


*We have to give our students guidance in developing their own pictures of themselves. What each must seek in his/her life never was, on land or sea.*

*If you follow your bliss, you put yourself on a kind of track that has been there all the while, waiting for you, and life that you ought to be living is the one you are living.*

*Wherever you are--if you are following your bliss, you are enjoying that refreshment, that life with you, all the time.*

**Joseph Campbell**

*The Power of Myth with Bill Moyers*  
Doubleday, 1988



### *Inside This Issue...*

- ***Toward Inclusive Schools in Minnesota***
- ***Helen Keller National Center Seeks Applicants on Transition***

## Applicants Sought for Partners in Policymaking

The Minnesota Governor's Planning Council on Developmental Disabilities is currently seeking applicants from interested parents of young children with developmental disabilities, or adults with disabilities, to participate in Partners in Policymaking. Partners is a nine-month, competency-based leadership education program designed to provide information, training, resources, and skills building. Expenses are reimbursed for travel, lodging, meals, respite care, and personal attendant services. **Applications are due by December 10, 1993.** Contact: David Hancox, Minnesota Governor's Planning Council on Developmental Disabilities, 300 Centennial Office Building, 658 Cedar Street, St. Paul, Minnesota 55155. 612/297-7519, or 612/349-2560 (voice); 612/296-9962 (TDD).

## Participate on Transition Advisory Committee

Applications for appointment are requested to serve on the statewide Community Advisory Committee for the Transition Systems Improvement Initiative. The purpose of this committee is to provide a customer-centered forum for the development and refinement of transition services for youth with disabilities and their families. The Community Advisory Committee meets in the Twin Cities area 4 to 6 times each year. Appointments are for three years with reimbursement for expenses (stipends) available. Contact: Stephanie Corbey, Interagency Office on Transition Services, 924 Capitol Square Building, 550 Cedar Street, St. Paul, MN 55101. 612/296-5660.

## Health Care Forums Scheduled

The Coalition on Health Care for Persons with Disabilities and Chronic Conditions will sponsor Legislative Forums in several communities around the state on Saturdays, 9:00 a.m. to 12:30 p.m.:

**October 9:** Duluth, Ordean Building, 424 West Superior Street.

**October 23:** Rochester, Rochester Community College, 851 30th Avenue, SE, University Building, U-239-241.

**November 6:** Twin Cities, Courage Center, 3915 Golden Valley Road.

**November 13:** St. Cloud, Whitney Center, 1125 Northway Drive.

Contact: Tom Brick, 1-800-945-8913, or Mary Jo George, 1-800-582-5296.

## Changing the World continued from page one

Four years later, during the 1987-88 school year, Charlie was going to school in a segregated classroom for children with multiple disabilities inside a segregated school for children with disabilities, all the way across town from our house (recommended as "the program we have for children like Charlie"). I did whatever the "experts" told me to do, in the hopes that it would help, but I couldn't help asking questions. Halfway throughout the year, Charlie's new teacher slipped me an application to a program called Partners in Policymaking, which was offered by the Minnesota Governor's Planning Council on Developmental Disabilities. She told me it would be good to get some answers to my questions. The application required a commitment from me, that I would attend all the sessions and do the homework. In return, I was promised a free, intensive program that would give me tools and access to ideas.

At Partners, my 30 classmates and I had a chance to get to know national leaders like Ed Roberts, Ian Pumpian, and Lou Brown and real moms like Fran Smith and Betty Pendler who told us what was working out there. They taught us to use "people first language," and the history of the disability movement, from the parents' movement right up to People First. We learned about independent living, supported employment, assistive technology, and family support. We learned how to access the human service system. We learned about personal futures planning and whole life planning. We also learned how to participate in the policymaking process and how to work effectively with professionals and public servants. **We learned that we were the most reliable experts about what our kids needed, and about what we needed if we had disabilities ourselves.** This was the toughest learning I ever did, because it was so real and so important to me and my kids.

I don't remember how it happened, but slowly I became aware that I was no longer working on fixing Charlie so my family could "go back" into the real world: now I was working on changing the attitudes of all those ordinary people, so they would see the value of communities which include people with disabilities and all people. I was working to help my friends and neighbors see that we all live in one world. It is important to me to see to it that other children wouldn't grow up as I did: removed from any possibility of understanding the variety and richness of the human community, left without the ideas I needed to deal with disability in my own family.

In Partners, **I learned that I could stop trying to make Charlie into somebody he wasn't.** I went home from one session feeling as confident as I've ever felt, and told my husband, "Don't worry, it's okay, we don't have to change Charlie. **We just have to change the world.**" In Partners, **I learned that the way to change the world is to focus on what you need to live your life, to speak up, and to participate. We learned that people need to be in charge of their own lives.**

We learned to ask for what we needed to keep Charlie living with us, such as: personal care attendant services (to allow him to have some independence from me and to allow me to work full time); a power wheel chair, and an elevator at school. The ten minutes of classroom inclusion in 1989-90 has now expanded into full inclusion in the fifth grade. Through the use of facilitated communication and a computer, Charlie can now communicate! When I asked him what communication means, Charlie spelled, "POWER." He will also tell you, "I am a very smart boy." He is proud of himself. His classmates voted him "most popular" at the end of the year, and he is developing friendships with other kids both inside and outside of school. Friendships are the key. **Sustaining the positive force of friendship in Charlie's life is our real goal.**

For people with disabilities, change really happens in their schools, neighborhoods, and families and in the hearts of fine ordinary people. As Joe Shapiro points out in *No Pity*, Congress can sponsor this change by giving us the ADA, the DD Act, and IDEA, but we must take it to the people, one by one, before real change happens.

The DD Act made these outcomes possible. Please know that this legislation makes real and meaningful differences for people with disabilities and their families.

Copies of the full text of Sue Swenson's testimony may be requested from the Minnesota Governor's Planning Council. See address and phones, return address, page 4.

## Inclusive School Communities in Minnesota

As a new feature of *Futurity*, highlights from around the state will be contributed by the "Together We're Better Program", a collaborative program of the Institute on Community Integration (University of Minnesota) and the Minnesota Department of Education. The Institute on Community Integration serves as Minnesota's approved University Affiliated Program, funded in part by the Administration on Developmental Disabilities, Washington, D.C.

### Systems Change in Minnesota: Together We're Getting Better

The history of inclusion efforts in Minnesota and current initiatives in special and general education indicate that Minnesota has both the need for systemic change and the leadership to implement it. Promoting the inclusion of learners with disabilities in general education settings is essential to the creation of a system that positively supports the learning and participation of all students.

Minnesota was one of four newly funded states this past year by the U.S. Department of Education to lead a national effort in statewide educational systems change. The overall mission of the Together We're Better Program is to influence the development of an effective educational system that supports the membership, participation, and learning of all students. The project began in October of 1992 and will continue through 1997.

Initially, the systems change project has established formal partnerships with three school districts: Owatonna, St. Cloud, and Moorhead. Partnerships with other school districts will be formed in the next few years. In addition, an Inclusion Mentorship Program that involves twelve teams from throughout Minnesota has been created. These teams facilitate the Partners for Inclusion Support Groups as announced below.

A mutual partnership between general and special education can and should be established to address shared purposes within each school system. "Together we will improve opportunities and outcomes for all children and youth in Minnesota," said Terri Vandercook, Co-director of the project.

### Partnership for Inclusion Support Groups Established

Together We're Better at the Institute on Community Integration, University of Minnesota, is sponsoring Partners for Inclusion Support Groups in many school districts. All persons interested in inclusive education are welcome. Contact: Laura Medwetz at 612/626-7225, or Mary McDevitt at 612/297-3619, or refer to the contact persons nearest you:

<u>Location</u>	<u>Contact</u>	<u>Phone Number</u>
Albert Lea	Linda Johnson	507/377-5825
Cokato	Barb Lhotka	612/286-2129
East Metro	Phil Sievers	612/457-8391
Faribault	Gary Hoganson	507/334-1864
Montevideo	Darlene Hamer	612/269-9243
St. Cloud	Steven Howe-Veenstra	612/252-2231
St. Francis	Kay Jackson	612/434-0471
Spring Valley	Peggy Willoughby	507/346-7358
West Metro	Tom Koch	612/933-9236

## A Story of Success!

Marta Susag is an included member of her school community. Marta is doing things we never thought possible seven years ago. Through parent training and empowerment we were able to dream and have visions for Marta, and then create supports to realize our dreams. Marta is in 5th grade in her home school. She uses a management aide to use facilitated communication. Because of this, she is doing fifth grade work. She is riding the regular bus with her brother and a bus aide.

She made her first communion. She is raising rabbits, and is a member of the Miesville Marigolds 4-H Club. She is funny, loving, and smart. She is happy. We've come a long way, and the story of success will continue! We are happy--which we weren't in 1986!

Contributed by  
Rebecca Susag (Marta's Mom)

### Call for Applications: Transition

The Helen Keller National Center will be selecting transition teams from ten states to receive assistance in providing training and technical assistance, addressing the needs of youth with deaf-blindness as they make the transition from school to adulthood. Applications must be submitted by November 1, 1993. Contact: Ms. Terry Carr, Project Coordinator, Helen Keller National Center-TAC, 111 Middle Neck Road, Sands Point, NY 11050. 516/944-8900, ext. 311. Local applicants should also contact: Joyce Surbeck, Minnesota State Dept. of Education, Capitol Square Bldg., Room 828, 550 Cedar St., St. Paul, MN 55101. 612/296-2548.

## Events

### October 21-23, 1993

Closing the Gap Conference, exploring microtechnology in special education and rehabilitation, will be held at the Radisson South Hotel and Hotel Sofitel, Minneapolis, MN. Preconference workshops are scheduled October 19-20. Contact: Closing the Gap, P.O. Box 68, Henderson, MN 56044. 612/248-3294.

### December 2-3, 1993

"Cooperative Villages for Learning" is a conference sponsored by Minnesota Educational Effectiveness Program (MEEP) and Together We're Better, University of Minnesota. Location: Hyatt Regency Hotel, Minneapolis. Contact: Terry Alvarado at 612/296-6464, or Pam Jones at 612/282-5086, Department of Education, 832 Capitol Square Building, 550 Cedar Street, St. Paul, MN 55101.

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## Lending Library

The following resources are available on loan; publications for three weeks; videotapes (VHS 1/2" cassette) for two weeks. The only cost to the borrower is the return postage.

***Working Together: Workplace Culture, Supported Employment, and Persons with Disabilities***, David Hagner and Dale Dileo, Brookline Books, 1993. Aimed at employers and program staffs, this book presents new approaches for assisting individuals with significant disabilities to achieve meaningful careers. Central to the approach are proven strategies based on the authors' experience with facilitating social inclusion into the cultures of the workplaces.

***Community-Based Curriculum: Instructional Strategies for Students with Severe Handicaps*** (Second Edition), Mary A Falvey, Paul H. Brookes Publishing Company, 1989. At the heart of curriculum designs are healthy partnerships with parents and significant others in the lives of students with severe disabilities. Strategies are provided regarding assessment and instruction, with focus on skill areas: community, domestic, recreation, employment, communication, and functional academic skills. Other topics include: transition, integration, and fostering friendships.

***Disability and the Family: A Guide to Decisions for Adulthood***, H.R. Turnbull, III, A.P. Turnbull, G.J. Bronicki, J.A. Summers, C. Roeder-Gordon. Four sections address areas for planning for the future: decision-making, financial planning and government benefits, life in the community, and advocacy. This book will help families to answer the fundamental question: "Just who is going to be making the decisions about my son's or daughter's future?"

## Federal Issues Forum--October 21, 1993 "Providing Quality Services in Changing Times"

On Thursday, October 21, 1993, the Minnesota Developmental Achievement Center Association (MnDACA) and the Governor's Planning Council on Developmental Disabilities will co-sponsor a federal issues forum, "Providing Quality Services in Changing Times." Location: Holiday Inn International, Interstate 494 and 34th Avenue, Bloomington, starting at 9:00 a.m.

The forum will focus on the questions, "What can providers of services for persons with developmental disabilities expect from the federal government, short-term and long-term?"

Speakers include: **Robert Gettings**, executive director, National Association of State Directors of Developmental Disabilities Services, Alexandria, VA; **Paul Marchand**, director of Governmental Affairs, The Arc, Washington, D.C., **Ellen Samuelson**, senior legislative assistant for health care, Office of Congressman Martin Sabo, Washington, D.C., and **David Doth**, deputy commissioner, Minnesota Department of Human Services, St. Paul.

A panel of advocates, providers, and agency personnel will respond and address the question, "Will change really improve the quality of services?"

Registration: \$85.00, which includes lunch and materials. Contact: MnDACA, 1821 University Avenue, Suite 277-S, St. Paul, MN 55104. 612/647-9200.

## Council Publications in Alternative Formats

Please tell your friends and colleagues who do not read print that several publications by the Minnesota Governor's Planning Council are now available in other formats, such as:

- 1) ***Futurity***, on audio cassette and is available through DRAGnet and the Children, Youth, and Family Consortium Clearinghouse (electronic bulletin boards);
- 2) ***Minnesotans Speak Out, Summary of Town Meetings***, audio cassette; and
- 3) ***Shifting Patterns***, publication in Braille and on audio cassette; and videotape with closed captions. See return address and telephones, below.

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## *Futurity*

**DEPARTMENT OF ADMINISTRATION**  
Governor's Planning Council on  
Developmental Disabilities  
300 Centennial Office Building  
658 Cedar Street, St. Paul, MN 55155

Roger Strand, Editor  
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# Futurity

November 1993

Minnesota Governor's Planning Council on Developmental Disabilities

## **Abuse, Neglect Higher for Children with Disabilities; Families Need Support**

"Children with disabilities are abused and neglected far more frequently than other children," was a conclusion reached in a recent federal study, conducted by the National Center on Child Abuse and Neglect. This is the first nationwide look at the extent of maltreatment among children with a physical, mental, or emotional disability.

Researchers found that children with disabilities are physically abused at twice the rate of other children, sexually abused a nearly twice the rate, and emotionally neglected at almost three times the rate.

The report underscores both the "tremendous economic and social pressures that are crushing" many families and the need to help them," said Senator Christopher Dodd, (D-Connecticut), who sponsored the 1988 legislation requiring the study.

The study was based on substantiated reports of maltreatment involving 1,834 children from 35 child protective agencies during a six month period in 1991.

Overall, children with disabilities are maltreated at 1.7 times the rate of other children. In nearly half of those abuse cases, the child's disability was at the root of the abuse or neglect. In all but 14 percent of cases studied involving a child with disabilities, the maltreatment was either committed or permitted by a child's primary caretaker, who is generally the mother, the authors of the report stated.

The study also documented that maltreatment often causes children to develop a disability. More than half of all children who were neglected developed a disability. Sixty-two percent of those children who were sexually abused, 48 percent who were emotionally abused, and 15 percent who were physically abused, experienced a disabling condition as a result of abuse/neglect.

For further information and for copies of the report, contact: National Clearinghouse on Child Abuse and Neglect, 1-800-FYI-3366.

Source: Associated Press release appearing in Minneapolis Star Tribune, October 7, 1993.

## ***The 'Yes-But' and 'Butwhatabout' Kids***

by Marsha Forest and Jack Pearpoint

We must get rid of the notion of "Yes-But Kids." There are no "Yes-Buts." There are only children. Recently we spoke at an educational conference entitled ALL KIDS BELONG TOGETHER. By the time the BUTS were finished, we concluded no one would be left in "regular" education. And when the "BUTS" stopped, the "Butwhatabouts" began. The logical outcome of that conference was an education system that "educates the best and simply manages and labels the rest."

It's easy to teach kids who are easy to teach. This is a truism. It is however a challenge to teach kids with challenging behaviors. Also common sense. Our answer is that "those kids" are the very ones who need us the most. In a delightful twist of logic, the education system NEEDS those children the most. "Those kids" are the very people who may restore spirit and meaning to our communities, nurture our sanity, and salvage our survival as a race of caring human beings.

Our values come clean in our reaction to these very students. They are the barometer of our values and our vision.

Source: *The Inclusion Papers: Strategies to Make Inclusion Work*, Inclusion Press, 1992.



## ***Inside This Issue...***

- ***Captioning Comes of Age for People Who are Deaf/Hearing Impaired***
- ***Metro Mobility Apologizes to Riders***

## **Futurity Available Via Consortium Electronic Clearinghouse**

In October 1993, this newsletter became available through The Consortium Electronic Clearinghouse, operated by the Children, Youth, and Family Consortium, University of Minnesota. This Clearinghouse is a new resource available to anyone with a personal computer, modem, telephone line, and communications software (such as Procomm, Kermit, Tincan, etc.). The Children, Youth, and Family Consortium was established in 1991 in an effort to bring together the varied competencies of the University of Minnesota and the vital resources of Minnesota's communities. Through collaborative efforts, the Consortium addresses critical health, education, and social policy concerns toward the improvement and well-being of Minnesota children, youth, and families. Contact: Children, Youth, and Family Consortium, University of Minnesota, 12 McNeal Hall, 1985 Buford Avenue, St. Paul, MN 55108. 612/626-1212.

## **Information for Seniors on "linkAGE LINE"**

The senior linkAGE LINE is a state-wide toll-free phone link that helps families, friends, and seniors find answers and services that will help older people remain as independent as possible. When family members or friends grow older, declining health or lack of financial resources can make staying independent difficult. One way to help is to gather information about services and how to locate them. The senior linkAGE Line puts you in touch with a network of organizations in Minnesota.

**Call: 1-800-333-2433**

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***Outstanding people have  
one thing in common:  
an absolute sense of  
mission.***

**Zig Ziglar**

## **Captioning Comes of Age!**

### **Communications Opened to People Who Are Deaf/Hard of Hearing**

In 1990, Congress passed the Television Decoder Circuitry Act (P.L. 101-431) mandating that by July 1, 1993, all TV sets manufactured and/or sold in the United States must include a built-in closed caption decoder. This legislation, plus the passage of the Americans with Disabilities Act (also passed in 1990), assures greater access and equality for over 4 million people in the United States who are deaf or have hearing loss. Three out of 100 school children have hearing impairments. One out of 4 people over the age of 65 has a hearing loss.

Linda Moen from the Regional Services Center for the Deaf and Hard of Hearing (St. Paul) sees the day when captioning will be seen everywhere, including presidential addresses, movies, videos, commercials--everything. Currently, all network primetime shows are captioned. In addition, major sports, children's shows, news, and much of the programming on cable and public television is captioned. Captioning is also useful to others, for example it is helpful for teaching children reading and writing and for teaching English as a second language.

**How is a program captioned?** Using a master tape of a video production, a skilled captioner transcribes the dialogue, describes sound effects, and edits when necessary for readability. Captions are positioned where they are most clearly seen on the screen. They are timed against the dialogue to coincide closely with the audio portion of the program. Once approved, a new master is made by encoding the captioning data into a portion of the video signal not seen by viewers, but read by a decoder. Since this caption information is hidden, the viewer can choose to watch the program with captions on or off.

**How expensive is captioning?** Compared to total video production costs, captioning is a minor expense, and assures accessibility to approximately 10 percent of the viewing audience. Max Duckler of CaptionMax, a captioning service in Minneapolis estimated that a typical 10-minute program can be captioned for about \$400: a TV commercial costs about \$250.

For more information, contact: Norma Sciarra, CaptionMax 708 North First Street, Suite 131, Minneapolis, MN 55401. 612/341-3566.

## **Health Department Announces New Name: "Minnesota Children with Special Health Needs"**

Atashi Acharya, section chief in the Minnesota Department of Health, recently announced a name change for what has been known as "Services for Children with Handicaps." The new name for this statewide service is "Minnesota Children with Special Health Needs." The acronym: MCSHN (pronounced "mission"). This section remains part of the Maternal and Child Health Division at the Department of Health. For more information, contact: MCSHN, Minnesota Department of Health, 717 Delaware Street, SE, P.O. Box 9441, Minneapolis, MN 55440-9441. 612/623-5000.

## Metro Mobility Issues Public Apology to Riders

The Regional Transit Board and Metro Mobility recently extended apologies for the inconvenience endured by persons with disabilities as a result of major problems experienced during the transition to a centralized system. Stated in a recent news release (October 14, 1993), "Every available resource is being mobilized to fix the problems and get the system fully operational as soon as possible." The National Guard is expected to phase out its deployment of drivers by October 22, 1993. "Guardspersons have performed heroically in this difficult situation, and have drawn praise from the riders (and many others)."

"The best way to help clear up this situation," the announcement indicated, "is to limit calls to essential matters only, and to call during the slower periods--midday and late afternoon." When calling to make comments or complaints, call 612/221-0015. This will allow reservation operators to focus on reservations. The numbers are:

**Reservations:** 612/221-1928 (voice)  
612/221-0014 (TTY)

**Customer Service:** 612/221-1932 (voice)  
612/221-0014 (TTY)

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## Publications

*Learning Together: Lessons for Inclusion*, Institute on Community Integration, University of Minnesota, 1993. This is a resource designed to create a caring classroom community, grades K-4, an environment in which all children feel good about themselves and work together to support the active learning and valued membership of everyone. The lessons and poster are available for \$10.00. The lessons, posters, and nine children's books that accompany the lessons are available for \$50.00. Contact: Publications Office, Community Integration, University of Minnesota, 109 Pattee Hall, 150 Pillsbury Avenue, SE, Minneapolis, MN 55455. 612/624-4512.

*Celebrate the Earth*, Vinland National Center, 1993, is a curriculum designed to include people with disabilities when teaching about the environment. This resource is a product of an environmental education project that was funded by the Minnesota Legislature from the Minnesota Future Resources Fund, as recommended by the Legislative Commission on Minnesota Resources. Field tested units cover: introduction to nature; habitats; forest ecology, and wetlands. Learning activities in each unit address sensory experiences, community awareness, and natural resources. Available from: Vinland National Center, Lake Independence, P.O. Box 308, Laretto, MN 55357. 612/479-3555 (voice and TTY).

*Community Transition Interagency Committees: 1993*, Minnesota Department of Education. This is the fifth annual report to the Minnesota Legislature assessing the progress of transition services to youth in preparation for adult life. Contents of the report describe: Minnesota's Systems Improvement Initiative; status report on local planning efforts; future goals; and available resources. Contact: Interagency Office on Transition Services, Minnesota Department of Education, 924 Capitol Square Building, 550 Cedar Street, St. Paul, MN 55101. 612/296-5660.

## Metro Mobility 'Issues Line' Established

The Metropolitan Center for Independent Living has started a Metro Mobility Issues Line to give riders an opportunity to share their experiences (good and bad) with Metro Mobility.

**The number is: 612/334-7495 (voice), or 642-2515 (TDD).**

You will have four minutes to record your information. Volunteers are needed to help with this effort.

## PACER Center Awarded Federal Transition Grant

A major three-year grant was recently awarded to the PACER Center in Minneapolis by the Maternal and Child Health Care: "Project Youth--A Statewide System of Family Centered Transition Planning and Care for Youth with Disabilities." A major goal will be provide education, resources, and support to families and youth. Information and training will also be provided to health care providers. Contact: PACER Center, 4826 Chicago Avenue South, Minneapolis, MN 55417-1098. 612/827-2966 (voice and TDD).

## Events

### December 2-3, 1993

"Cooperative Villages for Learning" is a conference sponsored by Minnesota Educational Effectiveness Program (MEEP) and Together We're Better, University of Minnesota. Location: Hyatt Regency Hotel, Minneapolis. Contact: Terry Alvarado at 612/296-6464, or Pam Jones at 612/282-5086, Department of Education, 832 Capitol Square Building, 550 Cedar Street, St. Paul, MN 55101.

### December 10, 1993 (7:30 p.m.)

The performance of *The Diary of Anne Frank*, written by Goodrich and Hackett, will be performed at the Apple Valley High School. An interpreter will be available for people who are deaf or have hearing impairment. Location: Apple Valley High School, 14450 Hayes Road, Apple Valley, MN 55124. Reservations must be made by November 29, 1993. Call: 612/423-7735 (voice); 612/423-7789 (TDD).

## Lending Library

The following resources are available on loan: publications for three weeks; videotapes (VHS 1/2" cassette) for two weeks. The only cost to the borrower is the return postage.

***Supported Employment: A Step-by-Step Guide***, PACER Center, 1992. This booklet is written for people who want to gain access to the workforce through supported employment, covering career planning, job development, supports, and integration.

***A Bibliography of Supported Employment and Transition Resources***, PACER Center, 1992. Abundant resources are described regarding: federal legislation, parental involvement, planning for transitions and the future, work incentives, plus lists of newsletters/journals, and training and information centers.

***Teaching the Possibilities: Resource Guide for Transition Planning--Post-Secondary Education and Training***, Minnesota Department of Education, 1992. This is a teaching guide for instructors, describing: preparation and planning, exploration of postsecondary options, services and accommodations, and available resources.

***The Whole Community Catalogue: Welcoming People with Disabilities into the Heart of Community Life***, David Wetherow (Ed.), Communitas, 1992. Collection of works from thinkers and doers at the leading edge of a paradigm shift--eliciting and supporting caring within the subtle fabric of human relationships.

## Reflections on Language

Language is a medium to express our innermost emotions and needs. Sometimes, we are not aware of the message we send with the words we choose, or our tone of voice. Recognizing that language has an impact can be the first step toward change. Often, we develop a jargon or different set of words to describe the everyday actions or feelings of others. Yet, these words are often identified as the very same "pet peeves" which bother us when applied to our own actions. Investigating how we use words was important to the individuals who shared the following stories.

\* \* \* \*

Carla got a job in a flower shop. About six weeks after she started, the employer asked me when she would be finished. I didn't understand. He said, "You said she was looking for a placement when you helped her in the interview. When does the placement end?" Carla was looking for a job, not a placement. The word "placement" had led the employer to believe it was a short-term position, not a real job.

\* \* \* \*

A visitor came one day at dinner time. Someone asked, "Who is feeding Rusty today?" The visitor asked enthusiastically what kind of pet Rusty was. Oh boy, was I embarrassed. Rusty is a man who simply needs some help at mealtimes. Now we are careful to say, "Who is having dinner with Rusty today?"

\* \* \* \*

Selina asked if we could go on an "outing." I asked what she would like to do. She said she needed food and wanted to go grocery shopping. Why is everything in her life an "outing?" Life boils down to a series of "outings" for people with disabilities. When is it time to just live?

**Source:** "Talking to Each Other," *Jumping the gap: more stories and ideas* (1993), Community Involvement Council, Tillsonburg, Ontario, pp. 28-29. *Jumping the gap* and a companion publication *Her shoes are brown* may be purchased for \$15.00, plus \$3.50 (U.S. dollars) for postage, payable to Tillsonburg and District Association for Community Living. Mail to: Community Involvement Council, Box 344, Tillsonburg, Ontario, Canada N4G 4H8.

## Futurity

**DEPARTMENT OF ADMINISTRATION**  
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# Futurity

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December 1993

Minnesota Governor's Planning Council on Developmental Disabilities

## Most People with Disabilities Don't Know about ADA

"While 41 percent of the American people are aware of the Americans with Disabilities Act (ADA), among those directly affected, people with disabilities themselves, only 29 percent are aware of the law." "This was the finding in a nationwide Harris poll (June, 1994)," stated Humphrey Taylor Harris president and chief executive officer. The poll, commissioned by the National Organization on Disability, was based on 1,253 telephone interviews.

The poll also documented that a large majority of the public supports greater access in making work places, transportation, and public buildings accessible to people with disabilities. The poll indicated 50 percent of the public is not moving fast enough in this area and also indicated that 92 percent of the public favors efforts to increase the number of people with disabilities in paid jobs. Previous polls documented that two-thirds of people with disabilities of working age are not employed and two-thirds of them want to and can work.

Source: Word from Washington, United Cerebral Palsy Associations, August/September 1993, p. 20.

## Deja Vu and ADA: Words of Timothy Cook, 1991

After all the excitement over the enactment of the Americans with Disabilities Act of 1990 (ADA), the disability community paused for well-deserved self-congratulations and celebrations over this legislative accomplishment. Surely the significance of Congress's actions in placing disability discrimination on a par with race discrimination could not be overstated.

Yet, there was a lingering sense of *deja vu* among those disability rights advocates who had been with this movement the longest. It was over fourteen years ago, when the issue was whether Section 504 of the federal Rehabilitation Act of 1973... would be enforced with strong administrative rules. After countless battles, when a relatively tough set of regulations finally was published on April 28, 1977, there were celebrations, much like those surrounding the enactment of the ADA, in the homes and work places of persons with disabilities across the nation.

But what effect did these wondrous new regulations, published fourteen years ago as our salvation, have on the forty-three million persons with disabilities in this country? The answer is--very little.

The issue today is whether persons with disabilities, a great number of whom were engaged in the enactment of the ADA, will rest on their laurels and legislative victories--allowing the ADA to accompany its legislative predecessors languishing in the hollows of nonenforcement.

If, by judicial or executive fiat, the ADA's desegregation mandate is watered down or abrogated, as has happened in section 504 enforcement, persons with disabilities will be deprived of their 'fairly won political victory,' and will continue to be subjected to segregation and exclusion.

Source: Abridged from Timothy M. Cook's article, "The Americans with Disabilities Act: The Move to Integration," *Temple Law Review* Vol. 64:2 (1991). Mr. Cook, executive director of the National Disability Action Center wrote this from his hospital bed, and died of cancer on October 21, 1991.

## Free ADA Information/ Consultation Calling Line Established:


**1-800-ADA-WORK,  
(or, 1-800-232-9675)**

The Job Accommodation Network is an international toll-free consulting service that provides information about job accommodation and the employability of people with functional limitations. The ADA-WORK calling line is staffed by the Job Accommodation Network.

When you dial 1-800-ADA-WORK, you will reach a professional consultant who can offer the following types of information:

- Technical information about requirements of barrier-free access and other issues;
- Ideas on how to change applicant interviewing procedures, job descriptions, and employment policies;
- Information about tens of thousands of manufactured products; and
- Current information about other service agencies, training programs and funding sources.

Calls are answered from 8:00 a.m. to 8 p.m. (Eastern Time), Monday through Thursday, and Friday from 8:00 a.m. to 5:00 p.m. Or leave a recorded message during other hours. This is a service provided by The President's Committee on Employment of People with Disabilities.



### Inside This Issue...

- *The Arc Reports on Segregated Employment among States*
- *Universal Screening Recommended for All Infants*
- *Congress Considers Worldwide Discrimination*

## Federal Legislation Introduced: Examination of Worldwide Disability Discrimination

On July 16, Senator Bob Dole (Kansas) introduced S.1256, the Disability Rights in American Foreign Policy Act of 1993.

This bill would amend the Foreign Assistance Act of 1961 to include examination of discrimination against people with disabilities in the annual report on human rights. Congressman Steny Hoyer (Maryland) has introduced a similar version in the House of Representatives.

The bill would provide the opportunity to extend the principles of the Americans with Disabilities Act into national human rights policy. Senator Dole would like to see a specific mandate for aid to people with disabilities to provide assistance to other countries with medical and rehabilitation services. "America's greatest export has been its concept of human rights. . .," said Senator Dole. The bill was referred to the Senate Committee on Foreign Affairs and has received considerable bipartisan support.

Source: *Word from Washington*, United Cerebral Palsy Associations, August/September 1993.

## Join National Coalition-- SAFE

Schools Are For Everyone (SAFE) is a national coalition of families, consumers, and advocates united in an effort to promote the availability of quality educational services to all students, including those with disabilities, in their neighborhood schools. SAFE is a one-issue organization. Strength lies in its singleness of purpose: working for FULL INCLUSION of all children.

Activities of SAFE include: educating decision-makers on legislation; coordinating letter-writing campaigns; publishing a newsletter, *The Safety Net*; and providing information and resources through a parent-professional network.

Dues: professional, \$30.00; parent/student, \$15.00. Send to: Schools Are For Everyone, P.O. Box 9503, Schenectady, NY 12309.

## The Arc Reports:

# 'States Foster Segregation'

By placing 82 percent of people with mental retardation in segregated employment services, state mental retardation and developmental disability agencies are perpetuating a myth that people with mental retardation are unemployable, according to a report released October 7, 1993, by The Arc, a national organization on mental retardation.

"A transition towards more inclusive settings is underway, but not quickly enough," said Alan Abeson, executive director for The Arc. "Research indicates that people with all levels of mental retardation, including those labeled 'profound' or 'severe,' can be, and have been, successfully employed. The challenge is to continue and accelerate this recognition of human potential and contribution. To do less would be an abdication of our mission," Abeson added.

In its *Status Report to the Nation on Inclusion in Employment*, The Arc evaluated the best available data from national and state studies to determine the extent to which people with mental retardation are being included, both physically and socially, along side co-workers without disabilities in the work place.

We want to make sure that people receiving services are getting the most appropriate employment services," Abeson said. "Sheltered' or segregated work environments unjustly sustain the notion that individuals with mental retardation are incapable of being contributing, tax-paying members of the work force and society. If adults with mental retardation are to become competitively employed, and be as independent as possible, they must receive services in integrated settings," Abeson added.

The Arc ranked each state on a combination of three measures of inclusive employment: 1) agency use of integrated employment environments in 1990; 2) the increase in agency use of integrated environments from 1988-1990; and 3) state use of supported employment. Connecticut, Alaska, Oregon, New Hampshire, and Colorado led the country in inclusive employment services. At the bottom of the state rankings were Indiana, Missouri, Arkansas, the District of Columbia, and Texas (in decreasing order). Minnesota ranked eighth on the list of states.

To accelerate and improve this trend, The Arc challenges the nation to advocate for and monitor implementation of the Americans with Disabilities Act, reduce sheltered employment settings, expand integrated environments, create additional public policy supporting integrated employment. Also needed is to establish a systematic approach to data collection on the employment status of people with mental retardation and other disabilities.

For copies of *Status Report on Inclusion in Employment*, contact: The Arc, National Headquarters, 500 East Border Street, Suite 300, Arlington, Texas 76010. 817/261-6003 (voice); 817/277-0553 (TDD).

*"Living well together*

*is the best revenge for the past."*

Burton Blatt

## 'Fix-Up' Home Accessibility Loans Available

The Fix-Up Fund Accessibility Loan Program is one of the programs offered by the Minnesota Housing Finance Agency (MHFA), which lends money to eligible homeowners for the purpose of making their homes more accessible for a person with a disability.

The Fix-Up Fund Accessibility Loan Program offers below market interest rates to homeowners whose projected gross annual household incomes do not exceed the maximum for the geographic area in which they reside and for household size. To be eligible to apply, the homeowner or a member of the family who resides in the homeowner's property must be "at risk of institutionalization," as certified by a county case manager. For more information, contact: Minnesota Housing Finance Agency, 400 Sibley Street, Suite 300, St. Paul, MN 55101-1998. 1-800-657-3960, or 612/296-7615.

## Call for Presentations

The 1994 International Parent-to-Parent Conference will be held April 29, 1994-May 2, 1994 at the Grove Park Inn, Ashville, North Carolina, and will be hosted by the Family Support Network of North Carolina. Presentations are requested for large sessions and 60-80 workshop sessions in the following areas: parent programs, family and friends, rest and renewal, services and transitions, the legislation and advocacy. Sessions will be interactive in nature and provide opportunities for reflections, discussion, and/or exchange of experiences and ideas. Contact: Holly Riddle, Executive Director, North Carolina Council on Developmental Disabilities, Department of Human Resources, 1508 Western Boulevard, Raleigh, NC 27606. 919/733-6566.

## Publications

*Developing Natural Supports in the Workplace: A Manual for Practitioners*; Syracuse University, July 1993. Despite the physical presence of people with developmental disabilities in work settings, many remain isolated on their jobs, with little opportunity to interact and develop supportive relationships with co-workers. This guide is the result of a collaborative effort between Syracuse University and Pioneer, Inc. The primary purpose of the project was to help people find community jobs, and become integral participants in their work places. Emphasis is placed on encouraging workers to participate in typical work routines with co-workers, and to enhance the individual's work and non-work social life among co-workers and other people in the community. A helpful quality checklist for evaluating a person's natural supports in the work place are provided in the Appendix. Contact: Center on Human Policy, Syracuse University, 200 Huntington Hall, Syracuse, NY 13244-2340. Also available on loan from the Lending Library. (See page 4.)

**CATALOG AND VIDEOTAPE:** *Laureate Talking Software for Special Needs*, Fall 1993 (Catalog); and *Software Solutions for Special Needs* (videotape, 8 minutes). This resource offers a variety of software packages and assistive technology devices designed to help children and adults to develop speech, language, reading and thinking skills at their own pace. Copies also available by contacting: Laureate Learning Systems, Inc., 110 East Spring Street, Winooski, VT 05404-1837. 1-800-562-6801.

## Futurity 'Cuts Budget Corners'

Due to budget constraints, the Governor's Planning Council on Developmental Disabilities will not be publishing *Futurity* in the months of January and July of 1994. To help us out, please let us know if you are receiving duplicate copies. Thank you for your understanding. (The Editor)

## December 11, 1993--'Partners' Application Deadline

The Minnesota Governor's Planning Council on Developmental Disabilities is currently seeking applications from interested parents of young children with developmental disabilities, or adults with disabilities, to participate in Partners in Policymaking. Partners is a nine-month, competency-based leadership education program designed to provide information, training, resources, and skills building. Expenses are reimbursed for travel, lodging, meals, respite care, and some personal attendant services. Applications are due December 11, 1993.

Contact: David Hancox, Minnesota Governor's Planning Council on Developmental Disabilities, 300 Centennial Office Building, 658 Cedar Street, St. Paul, Minnesota 55155. 612/297-7519, or 612/349-2560 (voice); 612/296-9962 (TDD).

## Information Center on Children and Youth Funded

The National Information Center for Children and Youth with Disabilities (NICHCY) is a national information and referral clearinghouse available to anyone. NICHCY is a project of the Academy for Education Development, which was recently awarded a 5-year grant from the U.S. Department of Education, Office of Special Education Programs. Services include: 1) personal responses to questions; 2) referrals to other organizations; 3) prepared information packets; and 4) technical assistance to family and professional groups. Free publications include: *News Digest*, a single subject newsletter which researches current topics regarding disabilities; and *Transition Summary*, which explores issues regarding the transition from school to adult life. Contact: NICHCY, Academy for Educational Development, P.O. Box 1492, Washington, D.C. 20013. 202/416-0300, or call the 800 operator (1-800-555-1212) for the new toll-free number.

## Lending Library

The following resources are available on loan; publications for three weeks; videotapes (VHS 1/2" cassette) for two weeks. The only cost to the borrower is the return postage.

**Publication:** *Developing Natural Supports in the Workplace: A Manual for Practitioners*, Syracuse University, July 1993. See description on page 3 under "Publications."

### **Publications About Early Intervention:**

1) *Enabling and Empowering Families: Principles and Guidelines for Practice*, C. Dunst, C. Trivette, and A. Deal, Brookline Books, 1988; and 2) *Developing Individualized Family Support Plans: A Training Manual*, T. Bennett, B. V. Lingerfelt, and D. E. Nelson, Brookline Books, 1990. These two publications go together for providing training to those involved in early intervention programs--working with families. Contents represent the aggregate of research and clinical work conducted at the Family, Infant, and Preschool Program in Morganton, North Carolina.

**Curriculum:** *Celebrate the Earth: An Environmental Education Curriculum for People with Varying Abilities*, Vinland Center, 1993. A comprehensive environmental education package which includes guidelines for adapting activities and working with inclusive groups. Units covered by age groupings include: introduction to nature (K-3); habitats (grades 4-7); forest ecology (grades 8-12); and wetlands (adults). For personal copy, contact: Vinland Center, Box 308, Loretto, MN 55357, or by phone at 612/479-3555.

## Early Intervention: All Infants Should Be Screened for Hearing Impairment

The National Institute of Health recommended last Spring 1993 that universal hearing screening be done before a baby leaves the hospital, and especially during the first three months of life. Currently, the only infants screened are those identified with one or more high risk factors, such as low birth weight or a family history of hearing impairment. These criteria fail to identify 50 to 70 percent of children born with hearing impairment.

In the United States, the average age of identification of hearing impairment is three years. Since the first three years of life are a critical period for developing speech and language skills, it is important to identify hearing problems as early as possible.

Recent technological advances have led to improved screening methods that can identify the majority of children with impaired hearing. Two tests for universal screening were recommended: a measurement of otoacoustic emission (OAE) and an auditory brainstem response (ABR) audiometry for infants who fail OAE testing.

The goal is to lower the average age of identification of hearing loss to six months by the year 2000.

## Council Publications in Alternative Formats

Please tell your friends and colleagues who do not read print that several publications by the Minnesota Governor's Planning Council are now available in other formats, such as:

- 1) *Futurity*, on audio cassette and is available through DRAGnet and Children, Youth, and Family Consortium Clearinghouse (electronic bulletin boards);
- 2) *Minnesotans Speak Out, Summary of Town Meetings*, audio cassette; and
- 3) *Shifting Patterns*, publication in Braille and on audio cassette; and videotape with closed captions. See return address and telephones, below.
- 4) *Never Too Early, Never Too Late*, videotape, is available with closed captions.

## Futurity

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