



Futurity

February 1993

Minnesota Governor's Planning Council on Developmental Disabilities

Empowering Families: Parents Vouch for 'Voucher Project'

Dakota County, with two year (September 1989 to October 1991) support from the Minnesota Governor's Planning Council on Developmental Disabilities, developed and implemented a project designed to place more control of service decision-making and government funds in the hands of families of children with disabilities. The inception of the Account Management Project (formerly called the Voucher Project) was families' dissatisfaction with the respite care they were receiving through county-contracted agencies. Families expressed concern that the county-contracted respite providers were too expensive, and were not flexible enough with their schedules. Families also complained that frequent personnel changes disrupted any continuity of care.

In addition to an evaluation conducted by Dakota County staff, a questionnaire was designed and distributed to the 25 participating families by an outside evaluator. This article summarizes the evaluation conducted by the Council. All respondents evaluated their experiences with the project as "excellent" or "good."

Prior to their participation in the project, approximately two-thirds (61.1 percent) stated that they had been "dissatisfied" or "very dissatisfied" with their respite care arrangements. Some reasons given for their dissatisfaction were:

- "Could not find providers to take care of our children."
- "Very high turnover rate, undependable, lack of privacy."
- "We felt very restricted in our options. We feel that we have been allowed more freedom to choose what best fits our needs."
- "I really was never unsatisfied. I just knew there must be a better, more economical way."
- "We did not feel comfortable with all providers as most of the time they were complete strangers to us."
- "A cycle of who's responsible and red tape."
- "Not enough options."

When asked how things have been different for themselves, their child, and/or their family since participating in the voucher project some of the following comments reflect the general response:

- "We are happier. We can go out to dinner, as a family. We have the support people we need, when we need them."
- "We really enjoyed the training meetings and the networking with other families."
- "We have more outings."
- "Increased freedom for the whole family."
- "Lower stress level--I know my son's workers will be here and my husband and I are able to have time alone weekly which is very important."
- "It has enabled us to meet the needs of our child without sacrificing the needs of our family."

Voucher Continued on page two

New Videotape: Minnesota Council Priorities Highlighted

Shifting Patterns is a new videotape production about how people have obtained the skills, knowledge, and allies they need so that they can take control of their lives. This videotape covers a number of projects sponsored by the Minnesota Governor's Planning Council on Developmental Disabilities, programs that carry out the Council's priority activity--"Leadership for Empowerment." *Shifting Patterns* is about how changes are taking place in beliefs and attitudes among individuals, families and communities.

Part 1 (Youth and Families) tells about how a Voucher Program helps families to choose among a range of options to meet their particular needs; how training in "Partners in Policymaking" helps parents to become involved in formulating public policies; how "Youth Leadership" programs can foster life-long friendships and can change the nature of communities for generations to come; and how Parents as Case Managers, has empowered families to regain control over their own destinies.

Part 2 (Adults) depicts how young adults can become involved in creating their Career Vision, such as at Kaposia, inc., in St. Paul.

Shifting Patterns continued on page two



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- *United Nations Agenda-- Education (Part 4)*
- *Youth Leadership Resources*
- *Mediation Service Update*

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Shifting Patterns

addition, through involvement in People First, adults gain the skills they need to speak out and to claim their rightful place in a democratic society. Through the "Partners in Policymaking" intensive training course, people have enriched their lives by learning how to influence public policy. In addition, "Personal Futures Planning" has helped to generate circles of friends who help people with a disabilities to realize the accomplishment of their personal goals.

Shifting Patterns is closed captioned. A companion booklet will available soon, and this publication will be sent to all those on the *Futurity* mailing list.

Copies of *Shifting Patterns** are available on a loan basis through the Lending Library of the Minnesota Governor's Planning Council on Developmental Disabilities, 300 Centennial Office Building, 658 Cedar Street, St. Paul, MN 55155. 612/296-4018 (voice only); 612/296-9962 (TDD only); or 612/297-7200 (FAX).

**Shifting Patterns* is the result of a federal grant on empowerment, funded in part through grant number 90DD0181 under provisions of the Developmental Disabilities Act of 1990 (P.L. 101-496). Content of this document does not necessarily reflect the position or policy of the Administration on Developmental Disabilities, Department of Health and Human Services, Washington, D.C.

Youth Leadership Videotape from Ridgedale YMCA

A closer look at the YMCA's "Leadership for Empowerment" program is available on videotape. This 15-minute video shows just how successful a fully-inclusive program can be. Young people who participated in a 4-day service trek became writers, videographers, editors, and actors as they documented their accomplishments. The demonstration and intervention project called *Beyond Boundaries* was sponsored by the Center for Children with Chronic Illness and Disabilities and the Ridgedale YMCA. A copy of the videotape, along with suggestions for its use, will be available soon. Contact: Harriet Kohen, Center for Children with Chronic Illness and Disability, University of Minnesota, 420 Delaware Street, SE, Box 721, Minneapolis, MN 55455. 612/626-4032.

Continued from page one
Voucher Program

- "There has been a lot less arguing in the house because of the voucher. Our daughter would stand at the end of the driveway and watch the other kids on bicycles, now that she has a special bike that looks like an adult tricycle, she can join them. It's great to see her join the other kids."

When asked what one thing about the voucher project was most important to them, the major themes flowing through their responses included more control in decision-making regarding providers and services, increased flexibility in use of monies to better address the specific needs of the child and family, reduction of stress, and empowerment:

- "The empowerment of the funds to do what is best for our child and family. We can make the decisions."
- "Funds for respite and the fact that I can hire anyone I feel comfortable with—people who know my daughter."
- "Being in control."
- "Flexibility—allows for family breaks and family unity."
- "The financial opportunities—we can purchase things that are great for our daughter. We recently purchased electrical switches, so she can help me in the kitchen and have some more choices for her to make."
- "We can chose our sitters, siblings of our child and our friends now get paid."
- "The creative approach to each family."

Parents reported overwhelmingly their desire to not return to the previous, traditional county arrangements. All parents reported that they would recommend this project to another parent of a child with a disability.

The author of the evaluation report, Sharon Patten, concluded:

The project takes an exciting and innovative initiative—a refreshing, bold, yet initial step in rethinking and redesigning service management at the county level. It speaks loudly, and with a humane voice to issues of flexibility, accessibility, choice, effectiveness, and partnerships. Also this project acknowledges and responds to the reality that families, not formal service providers, are the main source of care and support for children with disabilities, and that government needs to more effectively work in partnerships with families. The Dakota County Account Management Project has offered a new perspective, perhaps a new vision to the redesign of human service systems.

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

Youth Leadership Posters Available

"Leadership for Empowerment" posters are available from the YMCA project, funded by the Minnesota Governor's Planning Council on Developmental Disabilities. Each poster captures the face of youth of varying abilities becoming full contributing members of their community. Poster themes (each on a separate poster) within the Teen Leadership for Empowerment Program read: "Be Challenged," "Be Thoughtful," and "Be Leaders." Available on a first come, first serve basis, Write: YEP, Ridgedale YMCA, 12301 Ridgedale Avenue, Minnetonka, MN 55305. 612/544-7708.

United Nations Sets World Agenda on Disabilities Part Three in a Monthly Series

In an August 1992 publication, "World Program of Action Concerning Persons with Disabilities," the United Nations General Assembly outlined some of the following recommendations:

Education and Training

Member States should adopt policies which recognize the rights of persons with disabilities to equal educational opportunities with others. The education of persons with disabilities should as far as possible take place in the general school system. Compulsory education should include children with all ranges of disabilities, including the children with the most severe disabilities. There should be increased flexibility of application of regulations concerning admission age, promotion from class to class, and, when appropriate, in examination procedures. Basic criteria are to be met when developing educational services, which should be:

- **Individualized:** based on the assessed needs mutually agreed upon by authorities, administrators, parents, and students with disabilities and leading to clearly stated curriculum goals and short-term objectives which are regularly reviewed and where necessary revised;
- **Locally accessible:** within reasonable travelling distance of the pupil's home or residence except in special circumstances;
- **Comprehensive:** serving all persons with special needs irrespective of age or degree of disability, and such that no child of school age is excluded from educational provision on grounds of severity of disability or receives educational services significantly inferior to those enjoyed by any other students;
- **Array of services:** offering a range of choices commensurate with the range of special needs in any given community, including adult education;
- **Integrated settings:** requiring planning by all parties concerned; and
- **Parental involvement:** vital at all levels of the educational process, parents should be given the necessary support to provide as normal a family environment for the child with a disability as possible.

Note: Future issues of *Futurity* will list specific recommendations made in several additional areas: equalization of opportunities; legislation; physical environment; income maintenance and social security; employment; recreation; and culture.

'Buckle Up Line' Safeguards Passengers

Get immediate answers to your specific questions regarding: 1) Minnesota's Passenger Protection Laws; 2) child car seats; and 3) seat belts. Recorded messages are accessible 24 hours a day from any touch-tone telephone. The Buckle Up Line numbers are:

Metro: 612/427-2502

Toll-Free: 1-800/642-6408.

The Buckle Up Line is sponsored by the Minnesota Passenger Protection Program and Project Childsafe with funding from the Minnesota Department of Public Safety and the National Highway Traffic Safety Administration. For more information, contact: Minnesota Passenger Protection Program, 417 University Avenue, St. Paul, MN 55103-1995. 612/224-5121, or 1-800/223-5833, toll-free.

Events

March 11-13, 1993

A national conference, "Transition into Tomorrow's Workplace: Educating and Employing Individuals with Disabilities," will be held at the Minneapolis Hilton Hotel. Featured speakers: James Hoerner, professor at Virginia Technical College, and Alan Page, Minnesota Supreme Court Judge. Contact: Intermediate District 287, Hennepin Technical College, 1820 North Xenium Lane, Minneapolis, MN 55441. Call: Jane Kist, 1-800-345-4655, toll-free.

March 22, 1993

"Aging: Building Bridges 1993" is a conference sponsored by the Minnesota Chapter of the American Association on Mental Retardation. Keynote: Marcia Bryan, executive director of the Association of Residential Resources in Minnesota. Location: Metrodome Hilton, 1330 Industrial Boulevard, Minneapolis, MN. Contact: Bill Everett, President, 612/789-8841.

March 25-26, 1993

The Minnesota Association for Persons with Severe Handicaps will sponsor a 1993 Spring Conference entitled, "Interlocking Efforts: Together We Will Build Inclusive Communities." Location: Earle Brown Continuing Education Center, University of Minnesota--St. Paul Campus. Keynote address: Arthur Himmelman, senior fellow at the University of Minnesota's Humphrey Institute of Public Affairs. Contact: Mo Fahnestock, Institute on Community Integration, University of Minnesota, Pattee Hall, 150 Pillsbury Drive, Southeast, Minneapolis, MN 55455. 612/624-5042.

April 24, 1993

The Twin Cities Down Syndrome Association is sponsoring a regional conference, "Down to Earth: Everyday Issues," for parents and professionals at the Earle Brown Heritage Center, Brooklyn Center. Contact: Mary Maher, TCDSA, P.O. Box 22626, Minneapolis, MN 55422. 612/339-5544.

April 30 and May 1, 1993

Minnesota Head Injury Association, Conference, "In the Spotlight," Earle Brown Center, University of Minnesota, St. Paul Campus. Contact: Minnesota Head Injury Assoc., 2700 University Avenue, #12, St. Paul, MN 55114. 612/644-1121 or 1-800-669-6442, toll-free, (family/survivor helpline).

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.

Shifting Patterns, (Videotape, 35 minutes), Minnesota Governor's Planning Council on Developmental Disabilities, (1992). See description on page 2.

Just Families: That's All We Really Want To Be, Oregon Developmental Disabilities Council (videotape, 14 minutes), portrays stories of ordinary families who face the challenges of having a family member with disabilities. Booklet accompanies tape: *Families: Meeting Challenges, Promoting Change*, which tells the stories of the families who participated in Oregon's first Family Support programs.

Self-Advocacy and Persons with Developmental Disabilities: A Trainer's Manual, University of Oregon. This is a guide for starting a self-advocacy group. Accompanied by a videotape with two productions: *Speak for Yourself* (53 minutes); and *People First* (33 minutes).

Another Perfect Day, (videotape, 14 minutes), Minnesota Governor's Planning Council on Developmental Disabilities, a parody that can help service providers laugh at themselves; a good icebreaker in staff training.

Futurity is Available on Audio Cassette
Please tell you friends and associates who do not read print that they can request this monthly newsletter in audio cassette format. Call: 612/296-4018 (voice only); 612/296-9962 (TDD only).

Special Education Disputes Resolved Through Mediation Service

A new approach to resolving disputes between parents, school administrators, and special education personnel was initiated in Minnesota in August 1992. Issues can now be successfully mediated through the Minnesota Special Education Mediation Services (MNSEMS), which is sponsored by the Minnesota Department of Education and managed by the Minnesota Office of Dispute Resolution. Eleven disputes have been voluntarily submitted and successfully mediated during the last five months addressing a variety of issues, such as: appropriate educational environment, transportation, trust, communication, and eligibility for services.

"We are very pleased with the development of the system, the training and selection of mediators, and the use of the mediation process to resolve disputes," said Barbara Troolin, manager of monitoring and compliance for the Department of Education. "We will be listening to comments from the parties and mediators in order to continually evaluate progress," Troolin added.

Mediations have averaged about five hours in length, with an average of seven people participating in each conference, usually consisting of parents, advocates, school district superintendents, special education directors, teachers, and specialists. Each dispute has resulted in the development of written agreements between the parties. Mediation has the potential of saving time and money, when compared to traditional due process hearings.

Those who have experienced the mediation process have expressed strong support and appreciation for the service. Sample comments include: "It was very helpful. The mediator allowed both sides to do some venting in a 'safe' environment. The venting was long overdue and the mediator was a masterful listener." "It was a great experience ending a long-term bad experience and hopefully bringing about a positive future."

For more information, contact: Minnesota Special Education Mediation Services at 612/297-4635.

The logo for Futurity, featuring the word "Futurity" in a stylized, serif font. The letter 'F' is particularly large and prominent, with a decorative flourish extending from its top left. The rest of the word "uturity" is in a smaller, similar font.

TIME DATED MATERIAL



Futurity

March 1993

Minnesota Governor's Planning Council on Developmental Disabilities

Task Force Report 'Strongly Endorsed': Invest in Training System for Direct Care Providers and Families

On February 9, 1993, the Minnesota State Board of Technical Colleges "strongly endorsed" the report and recommendations submitted by State Technical College Task Force on Educational Opportunities for Developmental Disabilities Service Providers. The study and report was a result of legislation passed in 1991 that directed the State Board of Technical Colleges and an appointed Task Force to make recommendations for needed changes in both pre-service and continuing education programs for service providers and families. The report documents the need for and the establishment of a statewide, state-of-the-art training/practice system for direct care providers, including families.

"The need to establish such a system has been recognized and discussed for the past two decades," the Task Force observed. "In the meantime, persons with developmental disabilities have been waiting for almost two decades to receive adequate and appropriate state-of-the-art services from competently-trained direct care providers. This delay has resulted in missed opportunities for approximately 70,000 Minnesota citizens to live quality lives and to achieve their maximum potential in an inclusive community."

The following deficiencies in the current "non-system" were noted:

- A need to secure interagency cooperation and collaboration;
- A need to secure adequate funding to sustain a delivery system;
- A need to develop curriculum and training materials that emphasize skills and are competency-based;
- A need to effectively disseminate training and education materials and resources;
- A need to develop a process to evaluate education and training materials that is value- and outcome-based;
- A need to include incentives that will address low wage, high turnover, and staff retention problems.

Following are highlights from a number of detailed recommendations made in the report:

Funding:

- Training for direct care providers must become a priority and funding must be allocated to assure such training.
- Move resources from expensive, more restrictive, segregated services to home and community services.
- Establish a "training voucher system" where the voucher follows the person with developmental disabilities and the value of the voucher is tied to the needs of the person receiving services.
- As a general policy, training dollars should be available as new services are developed, and to develop and field test new curricula and approaches.
- The state should match any federal dollars if and when available for training.

Management/Interagency:

- State agency coordination/collaboration will need legislative direction.

Training continued on page three

Research Supports Inclusive Schools: Integration Yields Higher Performance

"The more that children with severe disabilities are included in regular education classes, the better they perform in school and social situations," said Pam Hunt, research coordinator for the California Research Institute of San Francisco State University. We know that other practices are very important, but they didn't come near to having the powerful link to success that integration had," she added.

Several variables were studied in five states: teacher training, principal involvement, and eight other factors shown to improve the education of students with disabilities. Parents and teachers of 312 students with severe disabilities were interviewed. Analysis of the data revealed that the children who attended mostly regular classes performed best in school and social situations and were better able to live independently.

"School districts need to do more than take students with severe disabilities from separate schools and put them into segregated classes in neighborhood schools," Hunt said. "Children should be included in the regular classrooms as much as possible. As we all know, physical integration does not always mean social integration."

Hunt said that this research may help shift debates about integration away from the question of morality to that of making an empirical stand, instead.

For more information, contact: Pam Hunt, C.R.I., Department of Special Education, San Francisco State University, 14 Tapia Drive, San Francisco, CA 94132. 415/955-4648.

Inside This Issue...

- *National Educators Call for Inclusive Schools*
- *World Agenda on Disabilities--Part Four*
- *Hillary Clinton Requests Suggestions on Health Care Reform*

Health Care Suggestions Requested

What problems are families and individuals encountering with the current U.S. health care system, and what can be done to solve those problems? Please share your experiences and offer potential solutions relating to medical care, insurance, or service for persons with disabilities. Send written testimony to:

Hillary Rodham Clinton, Chairwoman,
President's Task Force on National Health Reform,
White House, 1600 Pennsylvania Avenue, NW,
Washington, DC 20500.

Family Resources from The Arc

Siblings: Brothers and Sisters of People Who Have Mental Retardation (Fact Sheet, January 1993), provides an overview along with references for further reading about: 1) what are some of the concerns siblings have? 2) What are the benefits? 3) what positive actions can parents take? 4) what is being done to address concerns that siblings have?

Family Support: A Check for Quality (1993), provides a four-page, comprehensive check list for evaluating the quality of supports available to families. Specific quality indicators are provided in the areas of: information and planning, service availability, staffing, and program values. Helpful tips are provided for obtaining better supports to families. For copies, contact the Minnesota Governor's Planning Council on Developmental Disabilities (see return address and telephone numbers on page 4); or, Family Support Project, The Arc, National Headquarters, P.O. Box 1047, Arlington, TX 76004. 1-800-433-5255 (voice), or 1-800-855-1155.

**'Mainstreaming' means that you are a visitor.
'Inclusion' makes you part of the family.**

Howard P. Blackman
Executive Director
La Grange Area Department
of Special Education, Illinois

National Educators Call for Inclusive Schools

A group of state policymakers released a report (October 23, 1992) calling for a "fundamental shift" away from the current "separate and isolated system" of special education toward an inclusive system that focuses on outcomes for all students. "Transforming the current system will require changes in how education is organized, how teachers are trained, and how special and general education are funded," the authors of the report said.

In the fall of 1990, the National Association of State Boards of Education (NASBE) charged a 17-member Study Group on Special Education with assessing the state of special education, particularly in light of the school reform movement. In its final report, *Winners ALL: A Call for Inclusive Schools*, the group notes its work "is based on the premise that all children can and will learn, and this led to the belief that the dual special education/general education bureaucracies that exist today in most states have hindered collaboration between special and general educators."

The report highlights a number of efforts across the country to create inclusive schools. But, the report observes, "Unfortunately, these success stories of inclusion are often the result of a commitment by a few skilled individuals who run the specific programs, rather than a broad commitment for reform."

The group observed that the passage of P.L. 94-142--now called the Individuals with Disabilities Education Act (IDEA)--focused on access to public education (rather than outcomes) helped spawn a separate educational bureaucracy in which most children become mired, many never finish, and significant numbers do not make a successful transition to adulthood.

"In no way is the group suggesting that parent and student rights, be rescinded, [but] we must demand more of the system than it currently produces," the authors of the report said. Poor outcomes were attributed to "unnecessary segregation and labeling" of children for special services and the "ineffective" practice of mainstreaming, which "splinters" the academic and social lives of many students.

Specifically, the report calls on state boards of education to adopt three recommendations:

- Create a new belief system and vision for education that includes ALL students, and provide leadership by articulating goals for all students and then identifying the changes needed to meet those goals.
- Encourage and foster collaborative partnerships and joint training programs between general educators and special educators to encourage a greater capacity of both types of teachers to work with the diverse student population found in fully inclusive schools.
- Sever the link between funding, placement, and handicapping label. Funding requirements should not drive programming and placement decisions for students.

Source: *Counterpoint* (Winter 1992), National Association of State Directors of Special Education, pp. 1 and 9.

United Nations Sets World Agenda on Disabilities Part Four in a Monthly Series

In an August 1992 publication, "World Program of Action Concerning Persons with Disabilities," the United Nations General Assembly outlined some of the following recommendations relating to the creation of equal opportunities.

Legislation

Member States should:

- Ensure that persons with disabilities are granted equal opportunities with other citizens, eliminating any discriminatory practices.
- Draft human rights legislation, with attention given to conditions which may adversely affect the ability of persons with disabilities to exercise the rights and freedoms, such as education, work, social security, and protection from inhuman or degrading treatment.

Physical Environment

- Work towards making the physical environment accessible to all.
- Adopt a policy ensuring access to all new public buildings and facilities, public housing and public transport systems. Furthermore, encourage access to existing public buildings and facilities, housing and transport wherever feasible, especially taking advantage of renovation.
- Encourage the provision of support services to enable persons with disabilities to live as independently as possible in the community. In so doing, they should ensure that persons with a disability have the opportunity to develop and manage these services for themselves.

Note: Future issues of *Futurity* will list specific recommendations made in several additional areas relating to equalization of opportunities: income maintenance and social security; employment; recreation; and culture.

Training Continued from page one

- Develop a tracking system to allow the State to determine the amount of funds being spent on training, who is receiving training, and outcomes achieved.
- Modify all applicable rules/legislation so that the emphasis is on the guiding principles, as developed and approved by the Task Force.

Curricula:

- Tailor training to the audience.
- Training materials must be understandable and accessible.
- Establish mechanism to assure that curricula are regularly identified, updated, reviewed, and evaluated according to the guiding principles.

Delivery:

- Broaden the focus of training and make it accessible to existing generic community resources such as families, home health care, senior programs, special education, scouting programs, ancillary or paraprofessional staff.
- Competency-based training should be regularly available, including ongoing support and technical assistance.

Evaluation:

- Establish a process for ongoing review of curricula, and evaluate the impact on quality of services, as experienced by individuals and family members.
- Disseminate information about successful training approaches.

Incentives:

- Remove disincentives from rules, replacing with incentives.
- No certification should be required but training should provide flexible accreditation and promote career ladder opportunities.

"The above recommendations are a critical step toward the design, development, and implementation of training system, and a long overdue improvement in the quality of services provided to persons with developmental disabilities," the Task Force report concluded.

Copies of *State Technical Task Force on Educational Opportunities for Developmental Disabilities Service Providers*, an *Executive Summary*, and *Criteria for Competency Based Training* are available from the Governor's Planning Council on Developmental Disabilities Office. See return address and phone numbers on page 4.

Events

April 14-16, 1993

"Sharing Solutions through Partnerships in Aging and Developmental Disabilities" is an international conference sponsored by the Rehabilitation Research and Training Center Consortium on Aging and Developmental Disabilities, University of Akron, Ohio. Location: Holiday Inn, Cincinnati Airport Conference Center. Contact: Ruth Roberts, RRTC, Consortium on Aging and Developmental Disabilities, Institute for Life-Span Development and Gerontology, University of Akron, 179 Simmons Hall, Akron, Ohio 44325-4307. 216/972-7956.

April 15, 1993 (7:00 to 9:00 p.m.)

"Loss of Dreams: A Special Kind of Grief" is an evening out for caregivers, sponsored by the Wilder Foundation. Learn from Ted Bowman, senior trainer for Community Care Resources-- how to recognize and deal with the loss of an imagined future, or significant dreams. Location: Unity Unitarian Church, 732 Holly Avenue, St. Paul, MN. Contact: Wilder Foundation, CCR, 919 Lafond Avenue, St. Paul, MN 55104-2198. 612/642-4060.

Mark Your Calendar

June 1-5, 1993

The American Association on Mental Retardation will hold its 117 Annual Meeting, "A Bold New Approach," at the Washington Hilton Towers, Washington, DC. Contact: AAMR, 1719 Kalorama Road, NW, Washington, DC 20009-2683. 1-800-424-3688.

July 5-16, 1993

The McGill University Summer Institute in Integrated Education and Community will be held in Montreal, Quebec. Contact: Joan Spence, McGill Summer Institute, Centre for Educational Leadership, 3724 McTavish Street, Montreal, Quebec H3A 1Y2. 514/398-7044

Consumer Rights Project Serves Persons Who Are Deaf

The Metro Regional Service Center for Hearing Impaired People (RSC) and the Consumer Division of the Minnesota Attorney General's Office have joined together to offer a new Consumer Outreach Project for people who are deaf or hard of hearing. The Project can answer questions about consumer rights, help file complaints, help solve problems with businesses, and help find other resources to solve consumer related problems. Contact: Pam Bartels Gleason 612/297-1384 (TDD), or Joanna Morken Hardy 612/297-1393 (voice), or 612/296-9391 (TDD).

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Beyond Boundaries, (Videotape, 13:17 minutes, Closed Captioned), Ridgedale YMCA, Minnetonka, Minnesota (1993). Youth participated in a 4-day inclusive service trek became writers, videographers, editors, and actors as they documented their accomplishments, together. A documentary on youth leadership development/empowerment.

Kids Belong Together, (Videotape, approx. 30 minutes), People First Association of Lethbridge, Alberta, Canada. Through cohesive circles of friends, communities become a place for everyone. Parents and children with disabilities learn the importance of dreaming for the future and to share these dreams with others. Scenes primarily in elementary school settings.

Early Childhood: Least Restrictive Environment, A Policy of Inclusion, Minnesota Department of Education, (Videotape, 23 minutes). Examples from several schools in Minnesota illustrate the positive impacts made in the lives of children and their families through a policy of inclusiveness.

Minnesotans Speak Out, A Summary of Town Meetings Held Throughout Minnesota on Developmental Disabilities Issues (November 1992) is available on audio cassettes.

Quality Family Support Programs Sought

The Human Services Research Institute of Massachusetts is requesting nominations for quality family support programs from around the nation. Family support is *whatever it takes* for families who have a member with a disability to be just a family. The program may offer services, supports, and/or some amount of cash assistance. The following criteria may apply to quality programs: 1) is family driven (leads the decision making process); 2) values and respects families; 3) is easy to access and use; 4) is flexible; and 5) is family directed (families have a significant say as to how the program is run). To nominate a program, please send information about the program to Elissa Freud, HSRI, 2336 Massachusetts Avenue, Cambridge, Massachusetts 02140. 617/867-0426.

Publications

Teenagers at Risk: A National Perspective of State Level Services for Adolescents with Chronic Illness or Disability. National Center for Youth with Disabilities, 1993. A national study of state social, health, and education agencies concludes that: "The single, overwhelming impression the data give is that adolescents with chronic health care needs and disabilities are not considered a priority—either for funding or for programming." With the increased survival rate of youth with chronic health conditions, coupled with the relatively low priority given to services for teens, there is a strong challenge and need to provide social and psychological support for children and their families beyond childhood. "We must expand our horizons, our mandates, and resources to assure that all we have achieved in childhood is not lost in adolescence," the authors of the report implore. Specific recommendations are directed to national and state agencies. Contact: National Center for Youth with Disabilities University of Minnesota, Box 721—UMHC, 420 Delaware Street, Southeast, Minneapolis, MN 55455. 612/626-2825 (voice), or 1-800-333-6293, (toll-free), or 612/624-3939 (TDD).

Facilitated Communication Resource Guide, Annegret Schubert, Ed., Adriana Foundation, 1992. This guide is intended to be used in conjunction with hands-on training, and by those already using facilitated communication. Facilitated communication is about connecting and communicating with people who are unable to make their bodies do what they want them to do, to say the thoughts they have, to respond to what they hear, to control their behavior. The method involves physical, emotional, and verbal support to allow the person to access letters on a keyboard for spelling. Cost: \$22.00. Contact: The Adriana Foundation, 2001 Beacon Street, Suite 214, Brookline, MA 02146. 617/262-0387.

Futurity

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Futurity

April 1993

Minnesota Governor's Planning Council on Developmental Disabilities

Shifting Patterns: **Toward Empowerment and Self-Determination**

There is something new in the air that is helping us re-focus our vision of what is possible. Current buzz words like "empowerment," "self-determination," "self-advocacy," and "autonomy" represent a shifting pattern of viewing individuals with disabilities, families, and communities. Individuals can be empowered by obtaining more control of various aspects of their lives and are provided with opportunities to participate in their communities with dignity. According to Bob Williams (1989) "Self-determination is a ten dollar word for choice, or freedom, or a life filled with rising expectations, dignity, responsibility, and opportunity—it is a chance to live the American dream."

These concepts were explored in a recent publication and accompanying videotape, both entitled, *Shifting Patterns*, published and produced by the Minnesota Governor's Planning Council on Developmental Disabilities. The report summarizes the results of a national survey of "best practices" in empowerment and self-advocacy in the United States.

Changes in beliefs and attitudes were noted at the individual level, such as changes from the feeling of hopelessness to that of feeling hopeful. From self-doubt to that of believing in self. From seeing only deficits to that of looking at people's strengths.

Changes are happening in how we envision services and the role of professionals: from total reliance on experts to reliance on the "commonwealth" of communities; from "we" choose for "them" to consumers choosing for themselves; from having power over someone else to sharing power with and among everyone involved.

Changes are happening in our communities: from that of excluding certain people who seem different ("we"/"they") to including everyone ("all of us"); from seeing differences as inadequacies to seeing them as assets; and from viewing communities from one cultural perspective to that of a multicultural viewpoint.

Shifting patterns were documented in several projects taking place throughout America, such as: People First; Career Vision; Partners in Policymaking; Parents as Case Managers; Personal Futures Planning; Voucher Programs; and Youth Leadership. Regarding the latter, the concepts of self-determination and empowerment were captured best by Eric who was expected to climb "the tower," consisting of pegs projecting out of a 45 foot wall—"he took the first step and said he would not take another. Then, he took that step, and then the third."


A list of similar self-advocacy projects were identified from throughout the United States.

The publication, *Shifting Patterns*, will be sent to everyone on the *Futurity* mailing list. The publication and videotape will be sent to each state developmental disability council, university affiliated program, and protection and advocacy agency. Additional copies may be obtained from the Minnesota Governor's Planning Council on Developmental Disabilities. The videotape may be requested on a loan basis through the Lending Library. See page four.

Language of Us/Them

We like things
They fixate on objects
We try to make friends
They display attention seeking behavior
We take breaks
They display off task behavior
We stand up for ourselves
They are non-compliant
We have hobbies
They self-stim
We choose our friends wisely
They display poor peer socialization
We persevere
They persevere
We love people
They have dependencies on people
We go for a walk
They run away
We insist
They tantrum
We change our minds
They are disoriented and have short attention spans
We have talents
They have splinter skills
We are human
They are . . . ?

Mayer Shevin, in *The Inclusion Papers: Strategies to Make Inclusion Work*, by Jack Pearpoint, Marsha Forest, and Judith Snow, 1991.



Inside This Issue...

- ***Technology in Rural South Dakota***
- ***World Agenda on Disabilities (Part 5)***
- ***Inclusion for a Better Today***
by Judith Snow

♪ ♪ ♪ Dum-De-Dum-Dum ♪ ♪ ♪ **Futurity Goes DRAGnet**

This newsletter has broadened its audience to those who have access to electronic bulletin boards, via computers with telephone hook-ups. This service is made available by DRAGnet in Minnesota, and is available throughout the United States, Canada, and other countries. "DRAGnet" stands for Disability Resources, Activities, and Groups Network. The service can be accessed via a personal computer and modem, even for those requiring voice synthesizers.

How to gain access: Set terminal software to "ANSI Emulation" and communication parameters to "8N1." Then, dial 612/753-1943.

The idea for DRAGnet came from the simple desire to gather and share important disability-related information. It was created by and is operated by Gordon Gillesby of Andover, Minnesota.

Dragnet is available 24-hours-a-day providing over 200 disability conferences, events, computer and recreational software, educational text files, newsletters, and forums for self-expression. DRAGnet is also an outlet for accessing national bulletin boards: ADAnet, Disability Law Foundation, and various Independent Living programs throughout the country.

For a *Start-up Guide* and for more information, contact: Disability Rights Alliance, 1821 University Avenue, West, Suite 284-S, St. Paul, MN 55104. 612/645-8922 (Voice and TDD); 612/649-3073 (FAX).

STAR Hosts Funding Forum

The STAR (System of Technology to Achieve Results) Program will hold a forum, "To Sink or Swim? The Shallow Pool of Assistive Technology Funding," on May 18, 1993, 9:00 a.m. to 4:15 p.m., at the Radisson Hotel South, Bloomington, MN. Keynote address: Paul Hearne, President of the Dole Foundation for Employment of Persons with Disabilities. The Governor's Award for Excellence in Assistive Technology will also be presented at the forum. Fee: \$30.00 before May 1. Contact: STAR Program, 612/296-2771 (Voice); 612/296-9962 (TDD).

Technology Expands Reach of Family Services in Rural South Dakota

by Anne Floden Fallis

Imagine being poor and living on one of the isolated American Indian reservations in South Dakota—where the nearest shopping centers (and most major services and job opportunities) may be fifty to one hundred miles away. Now imagine what it's like to be a service provider under these conditions. The Dakota Bulletin Board Service (Dakota BBS) uses modern technology to provide service and information delivery to these families and to their service providers in isolated environments. The service is a computer networking system that enables instantaneous and interactive exchange of information using regular personal computers, modems, and rural phone lines.

The system is easy to use and does not require a high degree of computer literacy, nor expensive computers or equipment. Dakota BBS users can dial into the system with their computer modems much like making a phone call. The system has many functions and allows people to:

- Send and receive "mail," with a possible reply within minutes;
- Read current public announcements and news the instant they are posted;
- Join conference in which they can discuss specific issues with people from all over the world;
- Instantly download files of information, much like they might borrow a book from the library (only the library is at their fingertips); and
- Work on documents with teams from around the world.

On a typical day, an employee of Rural America Initiatives, a non-profit organization, might dial into the Dakota BBS and:

- Find out what meetings are scheduled for the week;
- Help a family member download a graphic to be used in a parent group's newsletter;
- Attend an on-line Alcoholic Anonymous meeting (with members from across the nation) during a break;
- Present a client's problem on an echo called, "Plain Talk," and receive feedback from social services and mental health professionals from South Dakota and Wyoming;
- Work on a grant with a consultant from the West Coast;
- Help a teen parent attend an "on-line" GED class.

Phone costs for linking with national and regional service providers are approximately \$25.00 per month. Expansion of services will soon include college classes and an American Indian arts-and-crafts catalog to market products of reservation families to national and international markets.

Abridged from *Report*, "Special Focus on Rural Families," Family Resource Coalition, November 1, 1992, page 20. Anne Floden Fallis is founder and executive director of Rural American Initiatives, Rural Route 1, Box 1845 Rapid City, South Dakota 57702. 605/341-3339, or by modem at Dakota BBS, 605/341-4552.

*Inclusion needs an 'includer,'
and it could be each of us.*

Nancy Ray, New York DD Planning Council, 1992

United Nations Sets World Agenda on Disabilities Part Five in a Monthly Series

In an August 1992 publication, "World Program of Action Concerning Persons with Disabilities," the United Nations General Assembly outlined some of the following recommendations relating to the creation of equal opportunities.

Prevention: Disabilities could be prevented through measures taken against malnutrition, environmental pollution, poor hygiene, inadequate prenatal and postnatal care, water-borne diseases and accidents of all types. The international community could make a major breakthrough against disabilities caused by poliomyelitis, tetanus, whooping-cough and diphtheria, and to a lesser extent tuberculosis, through a world-wide expansion of programs of immunization. . . Measures should be taken for the earliest possible detection of the symptoms and signs of impairment, to be followed immediately by the necessary curative or remedial action, which can prevent disability of, and at least lead to, significant reductions in the severity of disability that can often prevent its becoming a lasting condition. For early detection it is important to ensure adequate education and orientation of families and technical assistance to them.

Rehabilitation: In all rehabilitation efforts, emphasis should be placed on the abilities of the individual, whose integrity and dignity must be respected. The normal development and maturation process of children with disabilities should be given the maximum attention. The capacities of adults with disabilities to perform work and other activities should be utilized.

Important resources exist in the families of persons with disabilities and in their communities. In helping persons with disabilities, every effort should be made to keep their families together, to enable them to live in their own communities and to support family and community groups who are working with this objective. It is essential to take into account the customs and structures of the family and community and to promote their abilities to respond to the needs of the individual with a disability.

Note: Future issues of *Futurity* will list specific recommendations made in several additional areas relating to equalization of opportunities: income maintenance and social security; employment; recreation; and culture.

Publications

Professional Development and Training Directory, April through June 1993. This is a quarterly publication compiled by the Personnel Division, Community and Human Resource Development Section, Minnesota Department of Human Services. People who are preparing for and/or are working in the field of human services can benefit from the many training and continuing education resources available through the Department of Human Services, Community Colleges, Technical Colleges, and state operated residential facilities. For a current copy and to be placed on the mailing list, contact: Community and Human Resource Development Section, Personnel Division, Minnesota Department of Human Services, 444 Lafayette Road, St. Paul, MN 55155. 612/296-6626.

How to Develop a Community Network: A Guide for Those Seeking to Improve Services for Children with Special Health Care Needs, Pathfinder Resources, Inc., 1993. It is estimated that about ten percent of children and youth have a chronic disability. This guide provides a step-by-step process for mobilizing and utilizing resources through citizen participation. Price: \$9.95, payable to Pathfinder Resources, Suite 105, 2324 University Avenue, West, St. Paul, MN 55114. 612/647-6905.

Learn to Live with Epilepsy

The Epilepsy Foundation of Minnesota is sponsoring a four week training series to be held at its central office in St. Paul, Minnesota. The workshops will be held from 7:00 p.m. to 8:30 p.m. on four consecutive Mondays:

April 19, 1993--The Great Escape:
Coping with Stress

April 26, 1993--Who's in Control?

May 3, 1993--Anger? Friend or Foe?

May 10, 1993--Breaking the Rules: How to Win the Shame Game.

Contact: Kathy McGillivray, Epilepsy Foundation of Minnesota, 777 Raymond Avenue, St. Paul, MN 55114. 612/646-8675.

Events

April 20, 1993--Holiday Inn Shoreview

May 3, 1993--Holiday Inn Brainerd

"Living In One's Own Home: Toward an Understanding of Supported Living" is a one-day workshop at the above two locations, presented by Jane Wells of Creative Community Options. Fee: \$55.00. Contact: Creative Community Options, 4209 Oakmede Lane, White Bear Lake, MN 55110. 612/425-9263.

May 9-14, 1993

"Paraprofessionals. . .A Critical Link" is the second statewide conference for paraprofessionals in education, rehabilitation, and training. Contact: Teri Wallace, Institute on Community Integration, 6 Pattee Hall, 150 Pillsbury Drive, SE, Minneapolis, MN 55455. 612/626-7220.

June 25-29, 1993

"A Celebration of Stories!" is the 3rd International People First Conference to be held at the Regal Constellation Hotel, Toronto, Ontario, Canada. The People First movement was started by people who had been labelled mentally handicapped and could gain a voice in their communities by working together. Contact: Verlyn Rowett, People First of Canada, Kinsmen Building, York University, 4700 Keele Street, North York, Ontario M3J 1P3. 416/661-9611.

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.

Quality is . . . a Presentation by John O'Brien, (Videotape, One hour and 28 minutes). Measurement of program quality starts with each individual's perspective and satisfaction; toward a desirable personal future by discovering a vision, creating opportunities, and delivering supports.

How to Get Services by Being Assertive: For Parents of Children with Disabilities and Their Helpers (Revised, 1993), Family Resource Center on Disabilities, Chicago, Illinois. A process toward empowerment for parents and persons with disabilities. The authors state, "If you're not satisfied with your quest for services; if you're tired of all those 'nos' and 'can'ts'; and if you really want to do something about it--this book is for you.

Opening Doors: Strategies for Including All Students in Regular Education, C.B. Schaffner and B.E. Buswell, 1991. This publication describes the processes and approaches for successfully implementing inclusive education. Sections address team planning, student's strengths, relationships, adapting curriculum, and teaching methods. Note: This publication may be purchased for \$10.00, payable to PEAK Parent Center, Inc., Integration Project, 6055 Lehman Drive, Suite 101, Colorado Springs, CO 80918.

Shifting Patterns (Videotape, Closed Captioned, 35 minutes), Minnesota Governor's Planning Council on Developmental Disabilities, 1993. See description on page one.

Inclusion is Working Together for the Best Today We Can Have

by Judith Snow

The good news of inclusion is that its success is not measured by the yard stick that advocates and therapists use. As soon as a person is recognized as being a member present in the community's body, and as soon as the process of recognizing that person's gifts has begun, and above all, as soon as that person's gifts are structured into the activities of everyday life, then inclusion is present. In this way alone can the person with a disability genuinely be a community member working at making the community work for all, including themselves. Anything other than inclusion leaves the person waiting in their victim status--waiting for others to create a world where all their problems are solved and they can finally step on stage. This world hardly ever comes.

Inclusion is always available:

- even when people still have skills to learn or health problems to overcome.
- even when services are inadequate or there is not enough money.
- even when we haven't yet found the right person or worked out all the bugs in the plan.

Inclusion is including the vulnerable person in all the inadequacies, the "not yet's," the "can't gets." Inclusion is genuinely respecting and recognizing the person for who they are and what they are able to contribute, right now, in the life they are living right now--not the one they might have had, or maybe will have someday, when all the problems are solved. Inclusion recognizes neither *handicapped* nor *normal*, neither *us* nor *them*. All inclusion recognizes is that, if we work out today together--really together, today will be the best today we can have.

Inclusion demands that everyone be supported to be a sustainer of relationship and a responsible contributor to community. As we work to build the vision of inclusion, we will find that there are not some working for others, but that we all can work for each other. The success we achieve will make the successes we don't achieve much more bearable.

Excerpt from: Judith Snow, April 1992, "Not Idolizing the Average."

Futurity

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Minnesota Governor's Planning Council on Developmental Disabilities

Study Recommends Stronger Supports to Families: Cost Comparisons Reveal Few Incentives for In-home Care

The decision to care for a family member with a developmental disability at home is not without its consequences, especially in a society that provides little financial or other incentives to do so. "America's expenditures on child care are not supportive of families," observed authors Arnold Birenbaum and Herbert J. Cohen in a national study of 634 children and young adults with developmental disabilities.

Expenditures for in-home care were compared to out-of-home care. All of the expenses incurred by families and charitable organizations to maintain children and young adults with severe disabilities in their homes averaged about \$550 annually for those with autism and about \$950 annually for individuals with mental retardation. For children with mental retardation and physical disabilities, families had substantial expenses beyond the cost of programs and other caregivers. A few families had substantial expenses related to construction of ramps and other home modifications or to purchasing a van to accommodate a wheelchair.

Private expenditures to keep a child home seem insignificant when contrasted with the reported Medicaid and Supplemental Security Income (SSI) payments to care for a child in residential placements (e.g. foster care, group homes, community residences, Intermediate Care Facilities for Persons with Mental Retardation, and nursing homes). According to David Braddock (1987), the average costs of such out-of-home care were \$16,000 for the typical individual with autism and \$27,000 for an individual with severe mental retardation.

The average annual health care expenditure for children with autism was about \$1,000, and for young adults with autism about \$1,700. The average health care costs for all American children are \$414.

The following implications for policy and recommendations from this study included:

1. Because of their disability, health care requirements for children, adolescents, and adults should be viewed broadly so as to include personal care and family support.
2. Financing should promote family-centered care with the family regarded as the unit for receiving services. The tendency to look at individuals without seeing them as members of families results in a distorted view. It is unrealistic to believe that excellent services have been provided to children with developmental disabilities when they receive appropriate schooling but their parents and siblings obtain no assistance in bearing the physical, mental, emotional, and social burdens of care. In addition, families who care for their children with disabilities at home often experience substantial indirect cost that was calculated by the authors as "lost lifetime earnings." Nationally, among all mothers whose youngest child is between ages 6-13, 48 percent are in full-time paid employment and another 18 percent are in part-time employment. In this study, about one fourth of the mothers with children with severe disabilities worked full-time, and about 20 percent part-time, more than 20 percent

Support to Families continued on page two

Windows

by Milo Gilliland

*Through the windows of my being
I see a patch of silvered blue sky
I sense the tingling crispness of a
frosty dawn
The crunch of fallen leaves beneath
my feet.
A distant church bell and the traffic's
roar
The warm, furry nuzzling of a friendly
dog.*

*If, by chance, all these windows
should be closed to me
And yet I have leave to touch your
hand
To know your thoughts, your
meanings
Would I not still have windows to
the world
And thoughts to share, and light
within?*

Source: *Signals, News for People with Hearing and Vision Loss*, (February 1992), FIND, Inc., Minneapolis, MN, p. 2.

Inside This Issue...

**Quality and Common Sense
by Clarence Sundram
United Nations Agenda--
Income and Employment
ACT Presents:
"Sticks and Stones"**

ACT Presents "Sticks and Stones"

A premiere viewing of a video documentary, *Sticks and Stones: The Self-Advocacy Movement in Minnesota*, will be presented by Advocating Change Together, Inc., at 7:00 p.m., May 18, 1993, at the Minnesota History Center, St. Paul.

Contact: Advocating Change Together, Inc., 1821 University Avenue, Suite 363-S, St. Paul, MN 55104. 612/641-0297.

Continued from page one

Supports to Families

points below the national average. The indirect costs in family income due to the mothers' foregoing work were substantial.

3. Young adults with developmental disabilities continue to need appropriate programs and personal care after they have completed school, which calls for a systematic commitment of resources at state and federal levels.

4. Just as fresh thinking about long-term care for elderly citizens includes new ways to expand home care, so should thinking about children with developmental disabilities include many varieties of child care and family services. Financing and organizing of family supports and subsidies should be made as administratively simple as possible.

5. Expand Medicaid to increase the use of home- and community-based services.

6. Financial support for families is a necessity, and can be provided in a variety of ways, such as: tax credits or deductions, direct payment to families in the form of a subsidy, and direct services to the unpaid provider, ranging from training to respite care.

The authors concluded: People who share a household with a person who has a developmental disability carry a burden beyond those of most people. If policy makers address the immediate family as the unit that needs services due to a member's disability, then respite services and other family supports would be common rather than the rarity we found them to be. Empowerment of people with disabilities cannot ignore those who provide day-to-day care.

Source: Arnold Birenbaum and Herbert J. Cohen. (April 1993). "On the Importance of Helping Families: Policy Implications from a National Study," *Mental Retardation*, American Association on Mental Retardation, pp. 67-74.

Quality: Re-discovering Common Sense by Clarence J. Sundram

If we look at the service system as it has existed to date, it is clear that the customer of the service system primarily has been the government agency that certifies, operates, or funds the service system. Providers have had to satisfy the regulators and funders, not the people they serve. In fact, since the people being served had little choice about where they were going to receive services, what services they were going to receive, or how good or bad they were, their concerns were largely irrelevant. A significant challenge we are going to have to confront on this journey to a new world of person-centered, preference driven service/support systems is deciding what "empowerment" means.

There are two central tasks to assuring quality. The first is clearly articulating the values and expectations that will govern all aspects of services and supports that are provided. Would we be willing to live our own lives by these values, and have them guide the lives of our children?

Clearly such values ought to address the protective role of the system in assuring health and safety of all who are served. But, they should affirmatively address the promotive role of ensuring that people have the opportunities to live the lives they want; to have autonomy in decision-making to the extent they are capable and to have their decisions respected.

The second central task is to make a sustained effort to inculcate these values within the staffs of our agencies and within agencies we license or contract with to provide services and supports.

It is far less important to develop detailed regulations governing water temperature, fiber in the diet, and square footage against which to monitor. I am much more in favor of a minimalist approach to regulation that relies heavily on common sense and professional judgement, and less on detailed regulatory specifications.

I have seen too many Individual Habilitation Plans with detailed task analyses, and reams of measurable observation data, cataloging a several year long effort to teach someone to tie his/her shoelaces. Hasn't any one thought about buying velcro sneakers and letting the person go on with his/her life?

We ought to be able to rely on our common sense to see if values are actually being implemented by using yardsticks that have a bearing in anyone's lives and which are capable of being measured, even without a Ph.D.:

- comfort and personalization of the environment;
- living with persons of one's choice;
- spending time doing things that are meaningful and pleasurable;
- opportunities to form relationships outside the circle of roommates and paid staff.

When looking for ways to enhance the quality for the people being served, we ought not to overlook the obvious and fail to ask them what they want.

This common sense approach to quality assurance would also lend itself to increasing reliance on natural safeguards that exist in the community—co-workers, friends, neighbors—whose natural interactions provide the independent eyes and ears, yet monitor unobtrusively. The private policy that I believe will make such a difference is to make a more conscious and conscientious effort to open ourselves to such genuine human relationships with people who are "clients" of service system, which ultimately are the best protection and insurer of a quality that is free.

We must re-make ourselves before we can begin to change the world.

Source: Abridged from "Reinventing Quality: Exploring New Dimensions," *New Directions*, National Association of State Mental Retardation Program Directors, January 1993, p. 3.

United Nations Sets World Agenda on Disabilities Part Five in a Monthly Series

In an August 1992 publication, "World Program of Action Concerning Persons with Disabilities," the United Nations General Assembly outlined some of the following recommendations relating to the creation of equal opportunities for persons with disabilities throughout the world:

Income Maintenance and Social Security:

- Every Member State should ensure that persons with disabilities have equal opportunities to obtain all forms of income and social security.
- Social insurance systems such as social security should be reviewed to make certain that adequate benefits and services for prevention, rehabilitation and the equalization of opportunities are provided for persons with disabilities and their families.

Employment:

- Member states should ensure that persons with disabilities have equal opportunities for productive and gainful employment in the open labor market.
- Support the integration of persons with disabilities into open employment through a variety of measures, including the use of technical aids needed to do their work.
- Laws and regulations should not raise obstacles to the employment of persons with disabilities.

Note: Next month, *Futurity* will conclude this series with recommendations made regarding recreation and culture.

Publications

Leadership Training Manual: People First, National People First Project, Downsview, Ontario, 1987. The People First movement has given many individuals labeled with a mental disability a sense of self-worth and purpose. This guide is designed for those who want to know what the organization represents and how to start and operate a group. The book contains illustrations as well as step-by-step guidelines for members, leaders, and advisors involved in self-advocacy. Price \$10.00, Order No. 0-9693484-0-1, from: Roehrer Institute, Kinsmen Building, York University, 4700 Keele Street, North York, Ontario, Canada M3J 1P3. 416/661-9611.

Resource Manual For Youth with Disabilities, Their Families, and Health Care Professionals in Minnesota, Center for Children with Chronic Illness and Disability, 1992. The following information was gathered from agencies working with youth in Minnesota: programs (social and recreational); network services and publications; transportation; health, organizations; counseling; funding sources; residential and independent living; and transition to community living. Price: \$10.00. Contact: Annette Robles, Division of General Pediatrics and Adolescent Health, Box 721-UMHC, Harvard Street at East River Road, Minneapolis, MN 55455.

Idea Sampler to Promote Awareness of Fetal Alcohol Syndrome and Effects, Minnesota Department of Human Services, 1993. Fetal Alcohol Syndrome (FAS) and Fetal Alcohol Effects (FAE) are entirely preventable. By abstaining from any alcohol use during pregnancy, FAS and FAE can be avoided. Yet, only 55 percent of women of childbearing age have heard of FAS/FAE and its consequences. Over 100 agencies/organizations contributed toward this publication, including: conferences/training, client services, school curricula, and educational materials from brochures to posters. Contents also includes: history and background; signs and symptoms; extent of problem; sample news release and media suggestions; and a guide for producing print materials. Contact: Minnesota Prevention Resource Center, 2829 Verdale Avenue Anoka, MN 55303. 612/427-5310; or 800/247-1303, toll-free.

Training for Trainers Offered

Professionals are being sought to receive training, who then can offer training to personnel in day and residential programs. Phase One will consist of a training session in each module. Phase Two will provide a one-day training session on Learning to Teach/Adult Learning Styles. The following classes have been scheduled at Sheraton Midway, St. Paul, MN:

May 20, 1993: Providing Direct Services to Persons with Traumatic Brain Injury.

June 3, 1993: Promoting Self-Advocacy.

June 29, 1993: Introduction to Vocational Rehabilitation Services for Adults with Serious and Persistent Mental Illness.

September 2, 1993: Providing Meaningful Integrated Service for Aging Persons with Developmental Disabilities.

All modules are being developed as part of a collaborative grant from the Bush Foundation provided to the Minnesota Association of Rehabilitation Facilities (MARF), the Minnesota Developmental Achievement Center Association (MnDACA), and Brainerd Staples Technical College. Fee for each module: \$70.00. For more information, contact: Customized Training, Brainerd Staples Technical College, P.O. Box 99, Airport Road, Staples, MN 56479. 218/894-3726, or 1/800-247-6836.

Events

May 27-28, 1993

"Creating a Sales Culture: The Next Generation" is a training opportunity sponsored by Kaposia Works, inc. It will be held at the Holiday Inn-Shoreview, Minnesota, featuring Cary Griffin and Bob Niemiec on sales and marketing for supported employment. Contact: Kaposia Works, Inc., 380 East Lafayette Freeway, South, St. Paul, MN 55107-1216. 612/224-6974.

June 9-11, 1993

"A Celebration of Change: Give Birth Again to the Dream" is the 1993 Annual Conference sponsored by Minnesota Developmental Achievement Association and Minnesota Association of Rehabilitation Facilities. Location: Madden's on Gull Lake near Brainerd. For more information call: MARF, 612/646-0900; MnDACA, 612/647-9200.

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.

It's Never Too Early, It's Never Too Late (videotape and guide publication), by Beth Mount and Kay Zwernik, Metropolitan Council, 1989. Provides an introduction to Personal Futures Planning, a process for analyzing and building upon relationships, experiences, gifts, and capacities for envisioning an individual's future.

An Interview with Herb Lovett (videotape), Minnesota Governor's Planning Council on Developmental Disabilities. A totally positive approach to solving behavioral situations. Lovett is the author of *Cognitive Counseling and Persons with Special Needs: Adapting Behavioral Approaches to the Social Context*.

Families Facing Transition, Beach Center on Families and Disability, University of Kansas (1988). Powerful interviews with three families who confront change when youth with disabilities make the transition to adulthood.

Working: Stories of Supported Employment, Texas Planning Council on Developmental Disabilities (1991). People with developmental disabilities are successful in a variety of work settings.

Futurity is available on Audio Cassette.

Please tell your friends and associates who do not read print that they can request this monthly newsletter in audio cassette format. Call: 612/296-4018 (voice only; 612/296-9962 (TDD).

Systems Don't Change: People Do

Real change involves direct personal contact between people with disabilities and those without them. Each change in the experience of two or more people changes their attitudes, their lives or, one might say, their "biographies." A saying attributed to Jerome Miller goes "change enough biographies and you will change a system."

This is the opposite of the way we usually think. It is a "trickle-up" theory of social change rather than a "trickle-down one. It is a perspective which is less interested in "systems change" than world change.

Source: David B. Schwartz and Mark Friedman, "Rules for Funding Social Change for People with Disabilities," *Crossing the River*, p. 220.

Summer Institutes Scheduled on Transition to Adult Life

People who play a significant role in helping youth with disabilities to plan for and make the transition from school to adulthood are invited to participate in a Transition Summer Institute scheduled at the following locations:

June 23-25, 1993: Moorhead State University

July 14-16, 1993: St. Cloud University

Registration fee is \$50.00. Contact: Cheryl Bates, Minnesota Department of Education, 612/296-5660.

Futurity

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Minnesota Governor's Planning Council on Developmental Disabilities

June 1993

Personal Futures Planning: Building on Natural Supports, Making Connections

by Ian Pumpian

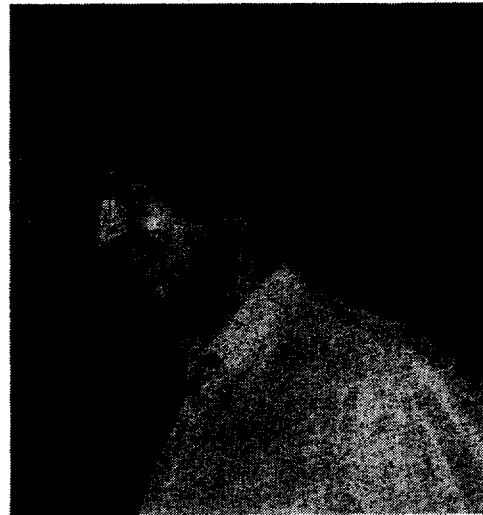
Ian Pumpian is a professor in the Department of Special Education at San Diego State University. This article is a summary of Dr. Pumpian's presentation to the Minnesota Governor's Planning Council on April 7, 1993.

Personal Futures Planning is a person-centered process designed to help a group of people craft a life of meaning and contribution for the person who is the focus of the planning. Through futures planning, significant people in a person's life, work together for social change for and with that individual. It is an ongoing process of mutual education, discovery, and adventure. (B. Mount and K. Zwernik, *Making Futures Happen*, 1990).

During the last decade, or so, the use of an empowerment process called "Personal-Centered Planning," (PCP) or "Personal Futures Planning" has swept the country. It has been extremely successful because it allows people with a disability to think hard about themselves and to express to others what they want out of life. Everyone involved in the process can see what part each has toward the fulfillment of another's dreams.

We have learned from some inherent weaknesses where the process sometimes breaks down:

- Participants may come away saying, "That was the best meeting I ever attended." This alludes one to think that PCP happens only once. Wrong, it is an ongoing process.
- Others may state that PCP was a great meeting but nothing has changed. Plans are made at PCP meetings, but there is no action taken after the meeting. Someone has to keep the process moving as an "anchor." Why engage in such a process if we can't deliver what the person desires? Unless someone is prepared to follow through with the person's choice, then there is no need to get the person's hopes up.
- Often, only a small number of people become involved in the PCP meetings and are responsible for too many people's plans. Too often the same people are showing up for planning sessions. Also, the facilitator, the person trained to do PCP, can be doing 20 plans for 20 people. It becomes impossible for that person to ensure that goals are being accomplished. It is critical that a wide range of people become involved: family members, relatives, neighbors, classmates, friends, etc. Those who do not view PCP as an opportunity to broaden a person's social network will experience less than satisfactory results. To enable people with disabilities to be included in their community, we need to involve more people from the community. Roles of staff and volunteers have to be ascribed as "community connectors." For example, brothers and sisters could be trained to help train their family member with a



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disability during the summer to ride the bus to work. We must figure out ways to mobilize people, get them involved, and to promote community action and service.

- We need to hear what people want before developing a program plan, not provide a few options and then develop a plan. The plan must be detailed--where the person wants to live, with whom, and what they want to accomplish. We must demystify the person's exceptionalities and focus upon their interests and personal goals.
- A person's circle of friends needs to go beyond family and staff. To do this, think of your own life--your experiences and interests. We continuously seek out those

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Standing by Words

I come, in conclusion, to the difference between "projecting" the future, and making a promise. The projecting of "futuurologists" uses the future as the safest possible context for whatever is desired; it binds one only to selfish interest. But making a promise binds one to someone else's future. If the promise is serious enough, one is brought to it by love, and in awe and fear. Fear, awe, and love bind us to no selfish aims, but to each other. We are speaking where we stand, and we shall stand afterwards in the presence of what we have said.

Wendell Berry (in *The Whole Community Catalogue*, David Wetherow (Ed.), Communitas, Inc., 1992, p 61.

Apply for Leadership Institute

An intense leadership training series has been designed by Learning Disabilities of Minnesota (LDM). Parents of children with learning disabilities and attention challenges and adults with disabilities are encouraged to participate to acquire and improve upon self-advocacy skills. "Leaders" attend 2-day sessions eight times a year between July 1993 and March 1994. Expenses such as travel, child care, and lodging are reimbursed. Contact: Lory Perryman, LDM Leadership Institute, 1821 University Avenue, #494-N, St. Paul, MN 55104-3389.

Toll-Free Number for Minnesota Relay Service Customers

The Minnesota Relay Service (MRS) Administration/ Customer Service now has a toll-free number, to be used for suggestions and concerns for a more effective telecommunication relay service: **1-800-657-3775 (Voice/TTY).**

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with similar interests and it is these very contacts that become (over time) an important part of our social network. If you have ever moved to a new community, it can take months and years to find meaningful relationships. Thus, the task of the PCP facilitator is to create situations where people with similar interests can come together. The National Association for School Curriculum and Development defines "culture" as the "voluntary nature of the way people behave." We need to match self-interest and collective good. Our challenge is to reach out and make connections with people who are already in the community.

The San Diego Experience:

College students, as part of their studies in community action, have participated in an "experiential" program where each student: 1) analyzes his/her own life-space; 2) receives life-space similarity awareness training (interaction between people with and without disabilities); and then develops an "inclusion in my life-space" proposal.

Simultaneously, people with disabilities in a variety of community settings take part in their personal-centered planning processes (with an outcome document that identifies the person's interests, needs, and skills). The two processes then come together where the college student's "inclusion proposals" are matched with the needs and interests of those engaged in implementing their PCP. Such matches are brought about in a variety of ways, e.g., social clubs, posters, ads in newspapers, or notes on bulletin boards.

For example, a person with a disability may have an interest in rock climbing or CB radios. The facilitator may not know anything about either activity. By using the inventories from college students, matches can be made, or overtures can be made to groups interested in the activity. The hope is that, once established, relationships become sustainable, propelled by natural interests.

A variety of "connections" have materialized: friendships, coworker relationships, roommates, job coaches, and mentorships. The possibilities are as diverse as our imaginations allow.

For additional information, contact: Ian Pumpian, Ph.D., Interwork Institute, San Diego State University, 5850 Hardy Avenue, Suite 112, San Diego, CA 92182. 619/594-2462.

Hennepin County Library Offers Summer Fun/Learning For the Whole Family

Summer 1993 need not be boring. The Hennepin County Library has scheduled free programs for children, which will be interpreted for those with hearing impairment.

Brookdale-Hennepin Area Library, 6125 Shingle Creek Parkway, Brooklyn Center. 612/569-3600 (Voice); 612/569-3606 (TDD). All of the following events will be held at 7:00 p.m.:

June 21--Mattie Clark, African American storyteller.

June 28--Bill Wiard, juggler/comedian.

July 12--Climb Theatre presents "The Ugly Duckling."

July 19--Master of Illusion, Curtis Hed.

July 26--Teatro Latino De Minnesota presents the "Love Bugs," a colorful world of diversity via insect puppets.

August 2--Wendy Baldinger, singing, storytelling, and movement.

August 9--James Gerholdt presents "Marvelous Reptiles."

Edina Community Library, 4701 West 50th Street, Edina. 612/922-1611:

August 3 (2:00 p.m.)--World Tree Puppets, folklore presented through hand puppets by Joan Mickelson.

Report to 1993 Minnesota Legislature: Transition Planning Needed for *All* Youth

Although efforts to assist in the preparation of young people with disabilities to make the transition from school to adulthood is now in place in Minnesota, there is no similar system in place to address the needs of *all* youth. This issue was addressed in a report to the Minnesota Legislature by the Task Force on Education and Employment Transitions, in response to a legislative mandate, entitled: *Making the First Chance a Real Chance for All: Bridging Education and Work for ALL Minnesota Youth and Adults*, written and published by the State Council on Vocational Technical Education.

"To be self-sufficient, contributing members of the workforce, Minnesota youth need to be prepared in a purposeful and timely manner," the authors of the report stated.

Attention to America's growing economic problems and the bleak outlook for young people in the workforce came about largely through such publications as *The Forgotten Half* (1988) and *America's Choice* (1990). Young American workers are unemployed at rates higher than the overall workforce, with unemployment rates for young workers of color 50 to 150 percent higher than their white peers. Around 10 percent of Minnesota's youth do not complete high school (*Minnesota's Forgotten Half*, 1991), with about 5,000 dropouts in 1990, and the loss of one entire high school graduation class every decade. The great majority of people entering the workforce receive no further education once they are in the workforce. Knowing that there is a direct relationship between amount of education and lifetime earnings, these trends are strong indicators of America's decrease in productivity and inability to compete in the world marketplace.

At the same time, more than half of Minnesota businesses report difficulty in recruiting skilled and technical workers. "A highly skilled workforce is essential for Minnesota's future," the authors stated. "Minnesota must provide an education and employment transitions system--complete and whole."

The Task Force agreed upon several basic assumptions, providing a foundation for a statewide plan, for example:

- All individuals can learn and become participating and contributing members of society.
- All individuals need to develop and continually improve their knowledge, skills, and personal qualities to meet their employment and life goals.
- Individuals of all ages can benefit from assistance in making education and employment transitions.
- There is a growing awareness of the value of collaboration as opposed to competition in how individuals and organizations relate to one another.

Major recommendations made to the Legislature included:

- Minnesota will create a comprehensive lifework development system.
- Education, business, and labor will be collaboratively responsible for integrating work-based learning into lifework preparation for all learners.
- Each learning center will develop clearly defined and understood learning outcomes, and will establish and maintain processes which invite, engage, and use learners, families, social networks, employers, and other community interests to ensure success for every learner.
- Establish a system to encourage, provide, and reward lifelong learning and continuous improvement of all education providers.
- Education, business, and labor will collaboratively establish world class performance standards for the education and employment transitions system.

In partial response to this report, the 1993 Minnesota Legislature created an Education and Employment Transition Council, which will oversee the implementation of youth apprenticeship and youth services programs.

For more information, contact: State Council on Vocational Technical Education, 366 Jackson Street, Suite 314, St. Paul, MN 55101. 612/296-4202.

Welcome to *Futurity!*

This may be the first time that you receive this newsletter. While updating our mailing list, many people, agencies, organizations were added. Thus, readership has expanded from 3,300 to over 5,000.

Thanks go to Ron Kaliszewski, staff member of the Governor's Planning Council on Developmental Disabilities, who successfully acquired needed software, learned, and processed our new mailing list.

Stories, announcements, and ideas are always welcome from the readers. **One request--when making address changes, please submit the old mailing label along with any new information.** We hope that you find *Futurity* worthwhile.

Events

June 17-18, 1993

"Surveillance of Alcohol Related Birth Defects: A First Step in Shaping Public Policy, Research, and Programs," is an informational and working conference that will be held at Riverwood Conference Center, Monticello, MN. Contact: Justine Schindeldecker, Minnesota Department of Health, 612/623-5548.

July 3-10, 1993

The National Convention of the National Federation of the Blind will be held at the Dallas-Fort Worth Hyatt-Regency, Texas. Contact: NFB, 1800 Johnson Street, Baltimore, MD 21230. 410/659-9317.

Mark Your Calendar

September 15-16, 1993: The Minnesota Semi-Independent Living Services, Inc. (MN SILS), will hold its annual conference at the Holiday Inn in St. Cloud. Contact: Sharon Polcher, MN SILS Conference Committee, H.O.M.E.S., Inc. 3535 West 9th Avenue, #135, Hibbing, MN 55746. 218/263-8911.

November 4-6, 1993: Learning Disabilities of Minnesota will hold its 24th Annual Conference, "Taking the Disability Out of Learning," at the Radisson Hotel South, Bloomington. Featured speakers: Marilyn Belgum and Jeannette Vos-Groenendal. Contact: LDM, 1821 University Avenue, #494N, St. Paul, MN 55104. 612/646-6136, or 1-800-488-4395, toll-free.

Lending Library

The following resources are available on loan; publications for three weeks; videotapes (VHS 1/2" cassette) and audio cassettes for two weeks.

The only cost to the borrower is the return postage.

Publication: *The Whole Community Catalogue: Welcoming People with Disabilities into the Heart of Community Life*, David Wetherow (Ed.), Communitas, 1992. A 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. (This item may be purchased for \$15.00: Communitas, Inc., P.O. Box 374, Manchester, Connecticut 06040. 203/645-8034.)

Publication: *Children with Tourette Syndrome: A Parent's Guide*, Tracy Haerle (Ed.), Woodbine House (1992). Parents and professionals describe Tourette Syndrome (a neurological disorder) addressing: diagnosis and treatment, child development and education, legal rights and remedies, support to families, and suggestions for further reading. (This item may be purchased directly from the publisher for \$14.95, plus \$3.50 shipping: Woodbine House, 5615 Fishers Lane, Rockville, MD 20852. 1-800-843-7323, toll-free.)

Publication in Braille: *Shifting Patterns*, Minnesota Governor's Planning Council on Developmental Disabilities, 1993, described in *Futurity*, April 1993.

Council publications on audio cassettes:

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

United Nations Sets World Agenda on Disabilities Sixth and Final Part of Monthly Series

In an August 1992 publication, *World Program of Action Concerning Persons with Disabilities*, the United Nations General Assembly outlined some of the following recommendations relating to the creation of equal opportunities for the estimated half billion persons with disabilities throughout the world:

Recreation

Member States should ensure that persons with disabilities have the same opportunities for recreational activities as other citizens. This involves possible use of restaurants, cinemas, theaters, libraries, as well as holiday resorts, sports arenas, hotels, beaches, and other places for recreation. **Services must be offered to all and not discriminate against persons with disabilities.** This involves, for instance, incorporating information on accessibility into their regular information to the public.

Culture

Ensure that persons with disabilities have the opportunity to utilize their creative, artistic and intellectual potential to the fullest, not only for their own benefit but also for the enrichment of the community. This includes access to cultural activities and making special arrangements to meet the needs of individuals with mental or sensory impairments, such as communication aids for people who are deaf, literature in Braille and/or cassettes for people with visual impairments, and reading material adapted to the individual's mental capacity.

During the past few months, the United Nations has been drafting a long-term plan, "Towards a Society for All--From Awareness to Action," to assist governments in making action plans extending to 2003--encompassing priorities to equalize opportunities and support independent living.

For more information, contact: Disability-Related Programs, Department of Public Information, Room S-1040, United Nations, New York, New York 10017. 212/963-0353.

Futurity

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