

# Futurity

Governor's Planning Council on Developmental Disabilities

May 1991

## Thoughts about Youth Leadership and Social Change

"People with diversity, including people with the label of disabilities, have for the most part been excluded from the discussions and participation in youth leadership. People who are seen as marginal have not been viewed as leaders. This frame of reference is not only inaccurate, but more importantly dangerous." These observations were recently stated by Jeff Strully, executive director of the Association for Community Living, Colorado, in a concept paper, *Thoughts about Youth Leadership* (April 4, 1991). Following are excerpts from Strully's thoughts about including all young people in youth leadership programs.

The future leaders of our country are the young people who are in our schools today. What these young people think, believe in, and act upon will determine, in part, what type of society we will have in the future. The need for young people to understand the responsibility of citizenship is one concept that is important to ensure that we have a participatory democracy.

We must realize that all young people are capable of leadership, a concept which can be explored by considering the following dimensions: vision; commitment and action; influence and inspiration; presence; and self-determination and interdependence.

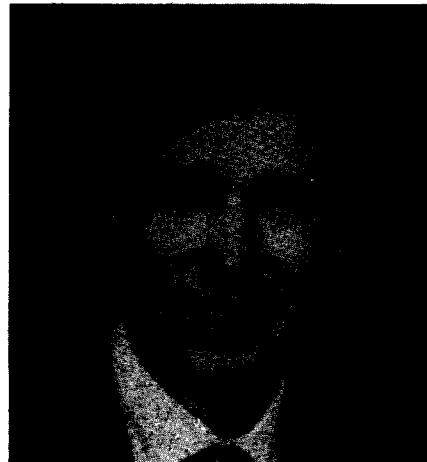
**Vision:** Having a vision for a desirable future for all young people is critical. The vision should include such issues as love, friends, control, power, money, opportunities, choices, and risk. Everyone is capable of having a desirable future, and everyone should be supported in trying to obtain their dreams.

**Commitment and Action:** Knowing your vision is one thing, acting upon it is another. Action needs to move toward a desirable future. We must see the need for long-term involvement in social change. Leadership is about people staying involved in the cause over time and not dropping out either when things get hot, things don't move quickly enough, or if the issues are not sexy.

**Influence and Inspiration:** Leadership is not about power for the sake of power. It is about influencing others so that positive change can take place. Influencing other people to take action or to act on behalf of another person is what we are attempting to achieve. This occurs, in part, through people's inspiration (as well as commitment) to the cause. Providing inspiration will rally people around creating positive change.

**Presence:** People's mere presence is one attribute of leadership. Just being a part of a group, being around when the issues are discussed or action being taken, is important. One's mere presence is a gift that should be cherished. Without people being around, individuals cannot make change.

Continued on page 4...



## Congratulations, Dr. Bruininks!

Robert H. Bruininks, professor of educational psychology, has been awarded the first Emma M. Birkmaier Professorship in Educational Leadership by the College of Education at the University of Minnesota. The three-year appointment is made in recognition of Bruininks' scholarly achievement and leadership in education. Bruininks is the current director of the Institute on Community Integration, University Affiliated Program, and is president of the American Association on Mental Retardation. In the mid-1970s, he served as the executive director of the Minnesota Governor's Planning Council on Developmental Disabilities. "Bob has already made a tremendous contribution to the College of Education," said Dean William Gardner. "I'm sure this professorship will allow him to expand his research and accomplish even more."

## Inside This Issue...

*A parent's dream IEP meeting*

*Adequate Health Care...  
A Human Right*



Andrew and his friends enjoy  
a music lesson at the Conant School.

## Resources

**Innovations: Statewide Systems Change Project**, is a new quarterly newsletter published by the University of New Hampshire. It is intended to inform classroom teachers, integration facilitators, consulting teachers, paraprofessionals, and anyone whose job it is to teach students what they need to know to be successful in classrooms, schools, and communities. A nominal fee may be charged. Contact: Office for Training and Educational Innovations, University of New Hampshire, The Concord Center, 10 Ferry Street, No. 14, Concord, New Hampshire 03301; 603/228-2084.

**Sexuality Rights Protection Policy**, Colorado Committee on Sexuality, 1991. This publication resulted in response to a request from Speaking for Ourselves, a self-advocacy group. Policy statements were developed and articulated under the sponsorship of the Colorado Developmental Disabilities Planning Council. This policy is to guide the community and empower persons with disabilities in Colorado to ensure that their inherent sexual rights and basic human needs are affirmed, defended, promoted, and respected, such as: 1) all persons have the right to privacy in order to have the opportunity for sexual expression; 2) all persons have a right to sexual expression, including the rights to develop sexual relationships, to choose sexual orientation, marital status, procreation and parenting; and 3) all persons have the right to access services, including education, health care, and other community resources. For copies, call: Rocky Mountain Resource and Training Institute, 1/800/255-DIRS, or 1/800/255-3477; or Colorado Developmental Disability Planning Council, (303) 894-2345.

## My Dream IEP Meeting *by Beth Dixon*

Wouldn't it be great if parents could look forward to their child's IEP (Individual Educational Plan) meetings? If they could go knowing they would walk out feeling good, proud, and satisfied? For many years, as the date of my son's IEP meeting drew near, knots would form in my stomach. I knew several things would characterize the meeting. The room would be filled with too many people, sometimes as many as 21, all eager to push for their own agendas. The meeting would begin with evaluations, present levels (of functioning), and a list of things that Andrew could not do. About then, the tension would grow into a sick feeling. Goals had been written by specialists who discussed how they were going to "fix" Andrew's problems, with the hopes of "getting him ready" for a regular classroom (7 out of 10 times, with 85 percent accuracy). By the time the meeting ended, my husband and I were so drained and depressed it was hard to function.

We've come a long way from those discouraging times. What has changed? Andrew is now a full-time member of a regular second grade class in our neighborhood school. We meet with just the immediate team (parents, teacher, integration facilitator, therapists) and begin with positive stories of what has happened in the classroom and on the playground, stories of friendships and skills that are growing. We list Andrew's strengths, and discuss his weaknesses by deciding what can be done to improve the quality of his day to make it meaningful for him. We talk about a beautiful child and his gifts, the things he is learning and what other children are learning from him. When we set goals, no one cares that Andrew doesn't isolate his index finger on command 2 out of 3 times. We care that he is doing the same thing as the rest of the class. We depend upon our dreams to set goals for Andrew that will help him succeed in society when his school days are over.

My husband and I now leave IEP meetings in a positive frame of mind and are very proud to be Andrew's parents. He is a wonderful little boy with many gifts to share, and they are now recognized. My dream is that all parents can experience this kind of IEP meeting and let those memories of former meetings slip into the past.

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### How to Create a Dream IEP Meeting

- ▶ Limit the number of people to key players.
- ▶ Have the meeting in a regular education setting.
- ▶ Make sure the team has a shared vision for the student.
- ▶ Start off with the positives. Try to imagine how it would feel to hear only the weaknesses of someone you love.
- ▶ Write goals that enhance the student's ability to participate in typical opportunities, now and in the future.
- ▶ Invite peers to be part of the IEP process.

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Permission to reprint this article was granted by Innovations Project of the Institute on Disability, University Affiliated Program, University of New Hampshire and the New Hampshire Special Education Bureau, funded by the U.S. Department of Education, Office of Special Education and Rehabilitative Services.

Beth Dixon, a business woman from Concord, New Hampshire, has four children, ages 8-20. Andrew is her youngest and attends second grade at Conant Elementary School, Concord, NH.

## Events

### June 5-8, 1991

National Conference on the Prevention of Primary and Secondary Disabilities, Atlanta, Cosponsored by the National Council on Disability, the Centers for Disease Control, and the Minority Health Professional Foundation. Contact: PACE Enterprises, 17 Executive Park Drive, Suite 200, Atlanta, GA 30329; 404/633-8610.

### June 23-23, 1991

Second Annual Meeting of All States on Assistive Technology, Kansas City, Missouri. Sponsored by the RESNA Technical Assistance Project, 1101 Connecticut Avenue, NW, Suite 700, Washington, DC 20036; 202/857-1140.

### July 24-27, 1991

Annual Conference of the Association on Handicapped Student Service Programs in Postsecondary Education, Minneapolis. Contact AHSSPPE, P.O. Box 21192, Columbus, OH 43221-0192; 614/488-4972, or Judy Schuck, cochair, Minneapolis Community College, 1501 Hennepin, Minneapolis, MN 55403; 612/341-7549.

### August 5-8, 1991

"Young Children, Families, and Professionals: Strategies for Community Intervention," sponsored by Minnesota Early Intervention Institute, Department of Education, will be held at St. John's University, Collegeville. For more information, contact: Jeanne Seigel, Institute Facilitator, Moorhead State University, Box 181, Moorhead, MN 56653; 218/299-5836.

### October 2-4, 1991

"Independent Living: Preparing for the 21st Century," Oakland, California. Sponsored by Center for Independent Living, National Council on Independent Living, and World Institute on Disability. Contact: Dianna Dal Aquilar, 2539 Telegraph Avenue, Berkeley, CA 94704; 415/841-4776 (voice), or 848-3101 (TDD).

### October 10-12, 1991

"Thirteenth International Conference on Learning Disabilities, Minneapolis. Sponsored by Council for Learning Disabilities, P.O. Box 40303, Overland Park, KS 66204; 913/492-8755.

## 'Adequate Health Care-A Fundamental Human Right, Not Privilege or Commodity,' says Ohio Task Force

The Health Insurance Task Force of the Ohio Developmental Disabilities Planning Council recently released its report and recommendations, *Insuring Health Care for People with Disabilities* (October 1990). Regina M. Sweeney, chair, pleaded in her cover letter in the report, "Join us in telling state and national leadership that comprehensive problems require a comprehensive solution--not more tinkering at the edges of a system that cannot be fixed. Please join us in insisting that national leadership shape a different kind of public policy, where adequate health care is no longer considered a privilege or a commodity, but a fundamental human right."

## Request for Award Nominations

Catholic Charities, within the Archdiocese of St. Paul and Minneapolis, annually gives an award to provide recognition to a person or program which has demonstrated success in enriching the dignity of persons with disabilities within the Catholic Community. Preference will be given to those involved in advocacy and social change. A \$200 stipend will be awarded. Nominations are due May 31, 1991. Contact: Mary Jane Steinhagen, 215 Old Sixth Street, St. Paul, MN 55102. 612/222-3001

### Educational Scholarships Available

Courage Center administers a Scholarship for People with Disabilities Program. The program assists people with disabilities to pursue educational goals or gain technical expertise beyond high school. Deadline for application is May 31, 1991. Contact: Director of Vocational Services, Courage Center, 3915 Golden Valley Road, Golden Valley, MN 55422; 612/520-0553.

### Technology Conference Scholarships Available

Financial assistance, or scholarships, are available to individuals with disabilities who wish to attend Closing the Gap Conference, October 17-19, 1991, Radisson South Hotel and Hotel Sofitel, Minneapolis. The 1991 Conference builds on a tradition of providing a comprehensive examination of the most current uses of technology by persons with disabilities and the professionals who work with them. Contact: STAR Program, 300 Centennial Building, 658 Cedar Street, St. Paul, MN 55155; 612/296-2771 (voice), or 612/296-9962 (TDD)

## Lending Library

The following videotapes (VHS, 1/2") are available on a two-week basis. The only cost to the borrower is the return postage.

**Teaching People with Developmental Disabilities**, Oregon Research Institute, Research Press, 1988. This series features four videotapes and four workbooks: 1) Task Analysis; 2) Prompting; 3) Reinforcement, and 4) Error Correction.

**Starting Over: Life After A Severe Head Injury**, North Carolina Council on Developmental Disabilities, provides methods and techniques for assisting individuals to transfer skills learned in rehabilitation settings to their homes.

**Families Facing Transition** (25 minutes) portrays three families with a member with a disability making a transition to adult life.

The following two productions are available on one cassette:

**Supported Employment: More Than Just A Job** (26 minutes), New Hampshire, features stories of several individuals whose lives are enriched by having "real work."

**A Waiting Work Force: Ready Willing and Disabled** (26 minutes), National Center for Research in Vocational Education, Ohio State University, emphasizes an untapped national resource--people with disabilities in the labor market.

## ►Continued from page 1 YOUTH

**Self-Determination and Interdependence:** "Self-determination must be imbedded within the context of interdependence. Only when people are bonded in groups for support and trust will the life and social skills of all members be enhanced." (P. Warfield-Coppock, Concept Paper on Youth Leadership and Self-Determination, 1990). Living with one another on a daily basis and demonstrating that all people can live, learn, work, play and be friends are acts of moral courage that has yet to be fully realized in this country.

The mission of Youth Leadership is to enhance and develop leadership skills in ALL of our young people. Leadership will be manifested in a variety of ways and settings-- statewide and local; public policy focus or in neighborhoods. Our young people can be empowered to realize and use their personal talents on behalf of themselves and others to achieve an inspired vision linked to committed action toward positive change.

## ►From page 3 HEALTH CARE

The Task Force called for a national, publicly administered health insurance system which guarantees adequate health care for all citizens. "The current national approach is so chaotic and, in many ways, wrong, that it is unredeemable without basic change," the Task Force observed. With respect to persons with disabilities they stated, "Theirs is an intimate crisis which can involve personal rejection by insurers and providers, endless hoops and red tape in government programs, benefits that are inadequate in both private and public coverage, and practices in each which are biased toward institutionalization and impoverishment."

"Americans deserve a pragmatic national response to the health insurance crisis, informed by the positive practices of the Canadian system," the Task Force recommended, adding: "The Task Force has found no basis in 21 months of research to fear that a publicly administered health insurance program in a nation such as this would impede its distinguished leadership in medical research and technology, or diminish the level of care Americans expect."

Request a copy of the report from: The Ohio Developmental Disabilities Planning Council, 35 East Chestnut Street, 5th Floor, Columbus, OH 43266-2505; 614/466-5205 (voice), or 614/644-5530 (TDD).

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300 Centennial Office Building  
658 Cedar Street, St. Paul, MN 55155

Roger Strand, Editor  
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612/296-9982 TDD

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Governor's Planning Council on Developmental Disabilities



June 1991

## **Barnes & Noble Launches 'Children with Special Needs Collection'**

Barnes & Noble, Inc. (New York, NY), the nation's largest bookseller, announced on April 1, 1991, a unique new program designed as a central resource for information about children with disabilities. The Children with Special Needs Collection, found in 500 B. Dalton Bookseller and Barnes & Noble bookstores nationwide, brings together for the first time a widely available, convenient, authoritative collection of books on children with disabilities, to serve their families, friends, teachers, and other professionals.

Steve Riggio, executive vice president of Barnes & Noble, is the driving force behind the development of the Children with Special Needs Collection. "This program was specifically designed to serve parents who seek broad sources of information, yet are stymied by an inability to find it," Riggio said.

Riggio, who has a three-year old daughter with Down syndrome shared his own frustrations in finding information. "I have personally felt lost in searching for well-written, informative books on the subject," said Riggio. "Once I found that there are indeed many excellent books available, I wanted to get the word out to other parents. This collection is the result of that desire," he added.

The collection will feature over 50 titles in several categories: specific disabilities, medical services and health care, educational opportunities and recreational activities, and supportive guides for parents and other relatives. The books will be prominently displayed in the Family and Child Care sections. A comprehensive brochure about the collection is available free to customers in all participating stores. Customers may also place special in-store orders for specific titles stocked by book distributors.

"Many parents, when learning they have a child with a disability, go to their local bookstore or library to seek information. Usually what they find is nothing. Now that will change," said Patricia McGill Smith, executive director of the National Parent Network on Disabilities. "We commend Barnes & Noble for starting this desperately needed program."

## **To be seen as having a disability**

by Nancy Ward

The following are excerpts from an article that appeared in *Links* (February 1990), published by National Association of Private Residential Resources (NAPRR). Nancy Ward works for People First in Lincoln, Nebraska. NAPRR executive director Joni Fritz was seated next to Ward on a flight from Lincoln and they soon found that they

## **Ten Quick and Easy Things To Do When You Meet AAC Users**

Here are some tips for when you meet a person who uses an alternative augmentative communicator:

Introduce yourself.

Ask user to show you how their communication system works.

Pause and wait for user to construct a message. Be Patient. It might take awhile.

Don't feel you have to keep taking all the time. Relax and get into this slower rhythm of exchanging information.

Give the user an opportunity to ask you questions or make comments.

Don't finish the user's sentences/words for him/her unless you get permission.

Interact at eye level if at all possible. Grab a chair if the user is in a wheelchair.

Pay attention to facial expressions and gestures.

Be honest. If you don't understand, admit it. Ask the user to try again.

Talk directly to the user, not to his/her friend.

From Blackstone, S. (1991) *Augmentative Communication News*.



*Inside This Issue...*

*What it is like to be seen as having a disability.*

*Recreation/leisure guidebooks published.*

Continued on page 2

# Event

June 19-21, 1991

"Energize 91" is the theme of the annual conference sponsored by the Minnesota Developmental Achievement Association, Minnesota Association of Rehabilitation Facilities, and the Staples Technical College. The conference will be held at Madden's Resort on Gull Lake near Brainerd. Contact: MnDACA at 612/647-9200, or MARF at 612/646-0900.

## Prize Offered for Computer Whizzes

John Hopkins University is conducting a national search for computer based application to help persons with physical or learning disabilities. The program is made possible by grants from the National Science Foundation and MCI Communication Corporation. A grand prize of \$10,000 and more than 100 other prizes will be awarded for the best ideas, systems, devices and computer programs developed by professionals, amateurs, and students. Entry deadline is August 23, 1991. For more information write to: Computing to Assist Persons with Disabilities, P.O. Box 1200, Laurel, MD 20723.

## Human Services R&D Center to offer

**3 days of training**

Reglstry Hotel, Bloomington, MN

**Thursday, July 11: Person-Centered Organizational Change** with Gail Jacob, Officer of TASH and Executive Director of Options in Community Living.

**Friday, July 12: Inclusive Community Building** with Kathy Bartholomew-Lorimer, Logan Sqaure Project, Chicago and Louisville.

**Wednesday, July 31: Current Understanding of Personal Futures Planning** with Beth Mount, Developer of Personal Futures Planning.

Call 612/227-3292, Pay Lyon, for details.

►Continued from page 1

## HAVING A DISABILITY

had interests in common. Fritz said, "Nancy's expression of what it means to be perceived as a person with a disability is far more articulate than anything I could have written."

### To be seen as having a disability in society's eyes. . .

. . . is to be stigmatized, isolated, and patronized. When we feel that we are more alike than different.

. . . is to have everyone controlling your life but you. You're not supposed to know how to speak for yourself. We are learning how to speak for ourselves. Who better knows what we want than us?

. . . is to be pitied and seen as not being able to do something. All we want is to be given a chance to contribute to society rather than society supporting us.

. . . is to go through a system that teaches you things you already know. All we want is for the system to see us as an individual and to help us with the things we need help with, not what the system thinks we need.

. . . is to be seen as different. All we want is the chance to make friends, to go to school or have a competitive job, and have a home just like everybody else.

. . . is not to be taken seriously. We want to show people that we know how to vote. We're taught what the issues are.

. . . is to be shut away in an institution away from the real world. We want to be given the same chance to make mistakes and to learn and grow from them just like everybody else.

. . . is to be a statistic because we aren't asked what supports we need to live a normal life. Who better than us will know what we need and want?

. . . is to be seen as handicapped. We want to be seen as people first, our disability second.

. . . is to be in a service system and have everyone telling you what's wrong with you. What we really need is to be shown how to do things for ourselves.

. . . is to be seen as being diagnosed with whatever evaluation people come up with. When we could have told them what the evaluation said, if given the chance to.

. . . is to have a strong cover so people can't see how much they hurt you by their labels. What we want is for society to see that we're more alike than we are different.

. . . is to go through each step of a program to progress to the next step when you already know steps one to five. When what we want is to be shown how to do things we don't know. How are people going to know what we want if they don't ask?

In the words of another: "To be seen as having a disability is not to get discouraged even if you want to and not to cry, and not to hurt, and not to be scared, and not to be angry, and not to be vulnerable, and not to laugh too loud, because if you do you only prove you have a disability even if you don't want to be treated that way. And so you become a nothing in a no-world and you are not."

## Resources

### ADA Information:

The U. S. Department of Justice has released a pocket guide on the *Americans with Disabilities Act* (ADA), a listing of statutory deadlines relative to ADA, and a fact sheet outlining Title III. Copies are available from Mr. James D. Bennett, Coordination and Review, Civil Rights Division, Department of Justice, 320 First Street, NW, Washington, D.C. 20534, 202/307-2220. Copies of ADA are also available in Braille, Cassette, Large Type and Flexible disk from the American Printing House for the Blind, P.O. Box 6085, Louisville, KY 40206; 502/895-2405.

In addition, the Eastern Paralyzed Veterans Association (EPVA) has published, *Understanding the ADA* which is a summary of the Act. to receive a free copy of the booklet, write EPVA, 7220 Astoria Boulevard, Jackson Heights, NY 11370-1178, or call 800/444-0120.

*Tools of the Trade: A Hands-On Program to Train Supported Employment Personnel*, Don Lavin, Kathie Prieve, and Anthony J. Gantenbein, Rise, Inc., 1991. This set of seven books was prepared for individuals to learn a variety of functional roles as supported employment specialists and for program managers and administrators. The volumes are interactive in nature with exercises and activities to assist the learner in demonstrating competencies. The books are entitled: 1) Ready, fire, aim! A manager's guide; 2) An introduction to supported employment; 3) Career planning and job development; 4) Strategies for training and ongoing supports; 5) Inclusion: the cornerstone of supported employment; 6) Case coordination: blueprint for success; and 7) Survival skills for supported employment specialists. Contact: Rise, Inc., 8406 Sunset Road, NE, Spring Lake Park, MN 55432. 612/786-8334.

*SAFE: Stopping AIDS through Functional Education*, Oregon Health Sciences University, Child Development and Rehabilitation Center, Portland, Oregon (1990). This is a comprehensive curriculum package designed to provide people who have developmental disabilities with information that can protect them from HIV infection. The curriculum makes no demands on the learner's ability to read. Eighteen lessons comprise video segments (videotapes and slides), activities, and illustrated handouts. Cost: \$60.00. Contact: Oregon Health Sciences University, CDRC Publications, University Affiliated Program, P.O. Box 574, Portland, OR 97207. 503/494-7522. Note: One copy is available on a two-week loan basis. Please see "Lending Library" on page 4.

*SSI New Opportunities for Children with Disabilities*, Mental Health Law Project. Due to expansion of eligibility criteria, an estimated 12,000 more children with severe disabilities may qualify each year for Supplementary Security Income (SSI). Billions of dollars in cash payments and Medicaid benefits will go previously ineligible children. Contact: MHLF, 1101 Fifteenth Street, NW, Suite 1212, Washington, DC 20005; 202/467-5730.

## Mark Your Calendars

**August 1, 1991**  
**(4:30 to 7:30 p.m.)**

"Adults with Deaf-Blindness Speak to Parents" is the theme of a workshop to be sponsored by In Touch, Inc. through a grant from Hilton Perkins Foundation. The workshop will be held at St. Stephens Church, 4439 West 50th Street, Edina. The workshop is to provide a forum for parents to develop a support network and to gain information about resources available to them. For more information and to register, contact: In Touch, Inc., 111 Third Avenue South, Suite 30, Minneapolis, MN 55404; 612/342-2066 TDD/voice.

**August 2, 1991**  
**(2:00 to 10:00 p.m.)**

Join the Celebration of the passage of the Americans with Disabilities Act at Lake Phalen Park, St. Paul, MN. Several agencies and organizations will sponsor this day of festivities. For more information, call Jan or Sylvia at Metropolitan Center for Independent Living, Inc., 612/646-6206 (voice/TDD).

**September 30 and**  
**October 1, 1991**

"Learning for Life" is a workshop to be held in the Twin Cities that will focus on the inclusion of children in their school communities. It will be led by Marsha Forest and Jack Pearpoint from Canada. Marsha Forest is director of the Centre for Integrated Education and Community. Jack Pearpoint has been a leader in the international literacy movement for the past 15 years, and is a lecturer, writer, and administrator in building inclusive communities. The workshop will be sponsored by the Hopkins School District, Minneapolis Children's Medical Center, and the Institute on Community Integration of the University of Minnesota. For more information, contact Tom Koch at 612/933-9236, or Gaye Rosenthal at 612/863-6870.

## Lending Library

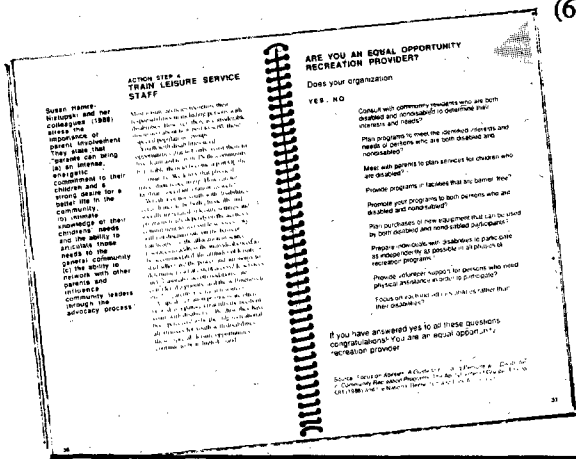
The following items are available on a two-week loan basis. The only cost to the borrower is the return postage.

**SAFE: Stopping Aids through Functional Education** (curriculum kit with slides and videotapes), Oregon Health Sciences University, Child Development and Rehabilitation Center, Portland, Oregon. (See description under "Resources on page 3.)

**Peer Tutoring: Children Helping Children** (VHS cassette, 23 minutes), Colorado Developmental Disabilities Council.

**The Sexuality of Your Child with Disabilities** (VHS cassette, 58 minutes).

**Assistive Technology: A Mother's Perspective** (VHS cassette, 15 minutes).



## SCOLA Publishes Guidebooks

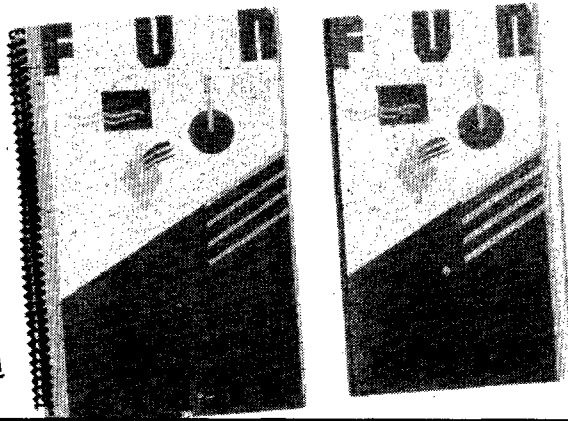
Arc Ramsey County has recently published two guidebooks which can help other communities to establish integrated community recreational programs. The guidebooks are a result of the SCOLA Project (School + Community = Opportunities for Leisure Activities). SCOLA was funded by the Minnesota Governor's Planning Council on Developmental Disabilities.

### **Community Recreation and Children with Developmental Disabilities: Fun Futures,**

Tip Ray, Arc Ramsey County, St. Paul, MN (1991). This booklet attempts to answer commonly asked questions generated by parents about how to encourage youth to be active in integrated community recreation. Emphasis is on how children need opportunities to play, be with friends, and have FUN!"

### **SCOLA Leisure Activity Fun Guide,**

Arc Ramsey County, Tip Ray, St. Paul, MN (1991). This guide highlights the activities of SCOLA that addressed the leisure needs of youth with developmental disabilities ages 14-21 years. Activities of the project included: parent empowerment training, self-advocacy training, technical assistance and training of leisure service providers, coalition building, and demonstration efforts. Free copies are available from: Arc Ramsey, 425 Etna Street, Suite 35, St. Paul, MN 55106 (612/778-1414, voice, or 612/778-0738, TDD).



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300 Centennial Office Building  
658 Cedar Street, St. Paul, MN 55155

Roger Strand, Editor  
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July 1991

## Zebley Decision Allows Reconsideration of SSI Eligibility for Children

The following article by Stephanie Butz, entitled "The Zebley Decision: It May Affect Your Patients," appeared in a recent newsletter published by the American Academy of Pediatrics.

In 1980, Brian Zebley, a child with congenital brain damage, was eligible for Supplemental Social Security Income because his disability qualified him according to the medical listings he needed to meet. Interestingly, two years later Brian was not eligible. At the time, eligibility for Children Under SSI was determined only by a medical listing, where as eligibility for adults was determined by a listing and by whether their disability kept them from working.

On February 20, 1991, the Supreme Court, in the Zebley Case, required that the Social Security Administration develop new standards. The new way of determining eligibility not only takes into consideration the medical listings but also the effect of the disability on the child's ability to function. The Supreme Court decision also requires that all children who applied for Social Security Income since January 1, 1980, be reconsidered under the new eligibility rules.

How will these families be located? The Social Security Administration will send out a letter to every child who applied; however, they will only send the letter to the address the child lived at when they applied. Public Service Announcements will also be used. The difficulty will be in locating these children. The children eligible to apply in 1980 may be as old as thirty now.

After a family receives the notice, they send back a postcard and the application process begins. Cases will be evaluated on the basis of evidence which may include an Activities of Daily Living questionnaire, and reports submitted by school teachers, family members, doctors, guidance counselors, etc. Cases will be reviewed by the Disability Determination Section of the Social Security Administration. It is believed that the total process of identifying and reviewing the cases will take twenty months.

You, the reader, may be aware of many of these families and will want to help identify them. Call your local Social Security Office for more information.

## Institute Awarded Funding for Regional Information Exchange

This fall, the Institute on Community Integration at the University of Minnesota will join the national network of Regional Information Exchange (Knowledge Diffusion) Programs. The U.S. Department of Education, National Institute on Disability and Rehabilitation Research awarded a \$200,000 grant to establish the North Central Regional Information Exchange (NCRIE). NCRIE will serve Region V, which encompasses Illinois, Indiana, Michigan, Minnesota, Ohio and Wisconsin.

NCRIE addresses the critical need within Region V to identify, document, and share information on exemplary practices and programs to encourage the adoption or adaptation of these practices and programs by state and local

## Governor's Planning Council on Developmental Disabilities Transferred to Department of Administration

The Minnesota 1991 Legislature, as one of its efforts to balance the budget, abolished the State Planning Agency. This agency has served as the host of administering agency of the Governor's Planning Council on Developmental Disabilities since 1972. In the same bill, the governor's Planning Council on Developmental Disabilities was transferred to the Department of Administration.

Thus far, this action has resulted in making only minor administrative changes. Our address and telephone numbers will remain the same, the same staff have been retained, and business will proceed as usual.

It should be noted that long-range planning for the State of Minnesota will now be conducted by the newly created Office of Strategic and Long Range Planning, which will begin its operations on July 1, 1991.

### Inside This Issue...

*New York State studies fiscal and economic impact of institution closures.*

*Minnesota Legislature adopts "People First" language in education statutes.*

Continued on page 3

## Mark Your Calendars

**August 2, 1991 (2:00-10:00 p.m.)**

Join the Celebration of the passage of the Americans with Disabilities Act at Lake Phalen Park, St. Paul, MN. Several agencies and organizations will sponsor this day of festivities. For more information, call Jan or Sylvia at Metropolitan Center for Independent Living, Inc., 612/646-6206 (voice/TDD).

**September 30 and October 1, 1991**

"Learning for Life" is a workshop to be held in the Twin Cities that will focus on the inclusion of children in their school communities. It will be led by Marsha Forest and Jack Pearpoint from Canada. Marsha Forest is director of the Centre for Integrated Education and Community. Jack Pearpoint has been a leader in the international literacy movement for the past 15 years, and is a lecturer, writer, and administrator in building inclusive communities. The workshop will be sponsored by the Hopkins School District, Minneapolis Children's Medical Center, and the Institute on Community Integration of the University of Minnesota. For more information, contact Tom Koch at 612/933-9236, or Gaye Rosenthal at 612/863-6870.

**November 21-23, 1991:**

TASH, The Association for Persons with Severe Handicaps, will hold its 18th Annual Conference at the Hilton Hotel and Towers, Washington, DC--"Building Futures." Attend preconference courses "TASH TECH" on November 20: legal training, facilitated communication, housing, inclusion, communication skills, and pediatric AIDS. Contact: TASH, 7010 Roosevelt Way, NE, Seattle, WA 98115-5650. 206/523-8446 (voice) 206/524-6198 (TDD).

## New York Studies Economic Impact of Developmental Center Closures

The Office of Mental Retardation and Developmental Disabilities (OMRDD) in the state of New York has released a report *The Fiscal and Economic Impact of Developmental Center Closure, 1987-1990* (November 7, 1990). An analysis was conducted of: 1) pre- and post-closure fiscal and employment data from the Rome, Craig, and Westchester Developmental Disabilities Service Offices (DDSOs) where the developmental center closures were completed; and 2) pre- and interim-closure data from the Newark, Bronx, and Manhattan DDSOs where the Developmental Centers will close within the next one to two years.

### Fiscal Findings

The average post-closure per diem operating costs (net of Federal Medicaid revenue) for the six DDSOs were approximately 9 percent lower than the pre-closure costs, dropping from \$149.52 million to \$135.69 million.

During the 3 to 5 years of transition toward closure (moving people from the institution to the community) costs increased because of staff serving fewer individuals. However, once the transition process was completed, the per diem costs dropped to levels consistent with the pre-closure costs.

The closure program can provide the state with significant capital savings if the closed campuses can be used for other state purposes. The savings result because of the cost differential between rehabilitation of the existing developmental center and construction of a new facility. For example, the closing of Rome and Craig developmental center campuses to provide other state services have approximated \$107 million.

In addition, substantial closure related savings may become possible through the use of the Medicaid Home and Community-Based Services Waiver.

### Economic Findings

There was little effect on state employee levels as a result of the closure program. For example, the establishment of correctional facilities in the Rome and Craig DDSOs increased state employment levels by approximately 50 percent (representing almost 1,500 new jobs).

There was a corresponding change in local personal income. In the Rome and Craig catchment areas, the annual increase in personal income was approximately \$47 million and \$10 million, respectively. These represented a 1.6 percent and 0.4 percent increase in the personal income of the entire catchment areas. Construction related earnings in the catchment areas were increased by 3.9 percent and 1.0 percent respectively.

In another report, *A Mandate for the 1990s: Closing Developmental Centers in New York State* (December, 1990), the Office of Mental Retardation and Developmental Disabilities proposes to develop a plan toward an accelerated closure of the remaining Developmental Centers by the year 2000. "Independent fiscal analyses of closure demonstrate that it is the most cost-effective course to take," the writers of the report stated. Mark N. Brandt, Director of the Arc NYS was quoted as saying, "Clearly the history of the past decade has shown us that even individuals with profound mental retardation can live within a small community setting with proper support. I think the institutional model is over."

Copies of these reports may be requested from: NYS Office of Mental Retardation and Developmental Disabilities, 44 Holland Avenue, Albany, NY 12229. 518/473-1997.

## Resources

*A Summary of Reports Prepared by State Developmental Disabilities Planning Councils: Independence, Productivity, Integration for People with Developmental Disabilities; Executive Summary*, (U.S. Government Printing Office: 1991-522-592/40172), Administration on Developmental Disabilities. This report (in addition to the 1990 Summary Report to Congress) represents the collective efforts of the Administration on Developmental Disabilities, 55 Developmental Disabilities Planning Councils, several University Affiliated Programs, national organizations, and many other individuals to respond to the legislative requirements of the Developmental Disabilities Assistance and Bill of Rights Act., as amended by P.L. 100-146. This volume summarizes the reports that were submitted by the Governors of the states and territories. Policy issues and recommendations are made relating to supports to individuals and families, education, employment and income, housing, health, and civil rights. For copies, contact: Administration on Developmental Disabilities, US Department of Health and Human Services, Washington, DC 20201.

*1990 Supported Employment Resource Guide*, National Association of Rehabilitation Facilities. This is a comprehensive listing of resources and information available about supported employment. Content includes: 1) training, technical assistance, and research resources (including federally funded projects, Rehabilitation Research and Training Centers, and University Affiliated Programs); 2) media resources (newsletters and information packets, audio visual and computer programs); 3) bibliographies; and 4) a cross referenced index. Contact: The National Association of Rehabilitation Facilities, P.O. Box 17675, Washington, DC 20041. 1/800/368-3513.

*The Consumers Guide to Long-Term Care Insurance*, Health Insurance Association of America. This question and answer guide can help to clarify information about health care coverage and long-term care. Most important, a list of questions are provided for the consumer to ask when shopping for and comparing health insurance options. A glossary of terms and a list for additional reading are provided. Contact: Health Insurance Association of America, 1001 Pennsylvania Avenue, NW, Washington, DC 20004-2599.

*The Americans with Disabilities Act: Questions and Answers*, U.S. Department of Justice, Civil Rights Division. The Americans with Disabilities Act guarantees equal opportunity for individuals with disabilities in public accommodations, employment, transportation, State and local government, and telecommunication. Everyone needs to be informed and involved so that this landmark legislation can be effectively implemented. Copies are available from the 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 only).

*Continued from page 1*

### INFORMATION EXCHANGE

agencies. Over the next three years, these priority areas will be addressed: Interagency collaboration and coordination in programs for transition from school to work; Emergent issues in supported employment programs; Parent-professional collaboration in the integration of individuals with disabilities in education, community living and employment.

The project begins in October 1991. A consumer and professional advisory committee will be established to assist in the identification validation, and sharing of information. Inquires should be directed to David R. Johnson at 612/624-1062 or Teri Wallace at 612/626-7220.

## Training Offered in Person-Centered Services

Human Services Research and Development Center has scheduled three days of training, "Quality Lives: Person Centered Services," at the Registry Hotel, I-494 at 24th Avenue, Bloomington.

**Thursday, July 11: Person-Centered Organizational Change** with Gail Jacob, Executive Director of Options in Community Living.

**Friday, July 12: Inclusive Community Building** with Kathy Bartholomew-Lorimer, Logan Square Project, Chicago and Louisville.

**Wednesday, July 31: Current Perspectives on Personal Futures Planning** with Beth Mount, Developer of Personal Futures Planning. Call Pat Lyon, 612/227-3292.

## Women's Chemical Dependency Assessment Workshops Scheduled

Chrysalis, a center for women, will be holding one-day training sessions regarding the assessment of women with chemical dependency. Gain an awareness of women's inner and outer worlds and how those worlds impact women's use of alcohol or other drugs. Dates and locations: July 12, Duluth; August 9, St. Cloud; and September 13, North Mankato. Contact: Leslie Scaramuzzo at Chrysalis East, 550 Rice Street, St. Paul, MN 55101. 612/222-2823.

## Lending Library

The following resources, including videotapes (VHS, 1/2"), are available on a two-week loan basis. The only cost to the borrower is the return postage.

**Be My Friend**, Tourette Syndrome Association, Inc., Minnesota Chapter, (10 minutes), promotes better understanding of Tourette syndrome, and provides illustrations of typical behaviors associated with this syndrome.

**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. This videotape is accompanied by a booklet **Families: Meeting Challenges, Promoting Change**, which tells the stories of the families who participated in Oregon's first Family Support programs.

**Self-Advocacy and People with Developmental Disabilities: Teachers Resource Book**, accompanied by two videotapes--**Speak for Yourself and People First**, University of Oregon. This training package covers the origin and philosophy of self-advocacy; procedures for starting new self-advocacy groups; and models for planning and conducting meetings and state conventions.

## Education Statutes To Reflect "People First" Language

The 1991 Minnesota Legislature passed a bill that instructs the revisor of statutes to delete each term in column A and to insert the term in column B within the education code:

Column A	Column B
Handicapped children	Children with a disability
Handicapping conditions	Disabling conditions
Handicapped pupil	Pupil with a disability
Nonhandicapped pupil	Pupil without disability
Nonhandicapped children	Children without a disability
Handicapped student	Pupil with a disability
Handicapped child	Child with a disability
Children with handicaps	Children without disability
Handicapped youth	Youth with a disability
Handicapped individuals	Individuals with a disability

*"It is extremely important that we not only build in respect and dignity toward people with disabilities in our statutes, but that these attitudes become second nature within our everyday language."*

Anne Henry, Legal Advocacy Attorney,  
(In response to this legislative accomplishment, stated.)

## Futurity

### MINNESOTA STATE PLANNING AGENCY

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

Roger Strand, Editor  
612/296-4018  
612/296-9982 TDD

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# Futurity

Governor's Planning Council on Developmental Disabilities

August 1991

## **Closing Institutions: Lessons Learned?** by Clarence J. Sundram

This article contains excerpts from a presentation given by Clarence J. Sundram at the Young Adult Institute Conference, April 24, 1991, in New York City. Sundram is the Commissioner of the New York Commission on Quality of Care for People with Mental Disabilities, Protection and Advocacy Agency. A complete copy of his address may be requested from: 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).

Today, I'd like to think aloud with you about closing institutions for persons with mental retardation. What lessons have we learned and how do they affect the role that each of us play in the development and execution of a policy to close institutions?.

Since the dark days of Willowbrook, both New York and the rest of the country have come to learn that no one really belongs in an institution. We have developed a body of experience that teaches that people with all forms, natures, and severity of disabilities can be supported and assisted to live in the community, and they generally benefit from such an option.

The lessons have been powerful, the evidence persuasive. A movement which began with a small group of parents, professionals, and advocates challenging the conventional wisdom and practice has *become* the conventional wisdom and practice. It sounds as if the story should have a happy ending, with a broad alliance opening the doors of institutions and restoring freedom to their inhabitants.

But wait. There are warning signs of trouble ahead. The familiar tension between conscience and convenience, about which David Rothman has written, is raising its ugly head.

The experiences which form our conscience teach us that many of the same things that we value in our own lives are of value in the lives of people with disabilities: where we choose to live and with whom; how we choose to spend our waking hours; the opportunity to form personal relationships with those of our choice, and so on. We have seen these experiences at work in many parts of the country--creating personal support systems to enable people to live their lives as they choose. It has not always been easy but we know how to do it and we know that the effort has enriched the lives of all involved.

We have also learned that it's not always convenient and it's usually not fast. Today's reform of closing institutions is also caught in the same dichotomy between conscience and convenience, and likewise risks overlooking the needs and desires of inhabitants in the rush to execute the emerging public policy.

There is added risk from the growing financial troubles sweeping the state and nation. The unfortunate lesson that fiscal policymakers seem to have learned is to close institutions and close them quickly, and to look for economies of scale in the development of large community residences of standard size and even larger day programs. The demands of convenience and efficiency produced a public policy that has resulted in a proliferation of 12-bed residences all over the state, to the virtual exclusion of other residential options. We seem to be approaching a policy much like Henry Ford's in producing the Model T: "Any color you want, as long as it's black."

*Continued on page 2*



### **Anne Henry Honored by Minnesota State Bar Association**

Anne L. Henry, staff attorney for the Legal Advocacy Project for Persons with Developmental Disabilities, was recently presented with the first Bernard P. Becker Award at the annual meeting of the Minnesota State Bar Association. She was recognized for her 16 years of service to persons with developmental disabilities and their families.

Henry was one of the lead counsel in the *Welsch* class action suit, which resulted in the dramatic improvement in conditions at regional treatment centers and the placement of hundreds of residents into alternative community living arrangements. Henry's

*Continued on page 2*

### *Inside This Issue...*

*New Cost of Care Rates in RTCs*

*Public Hearing on Assistive  
Technology*

*Paperwork Rebellion*

## RTCs Care Rates

On July 1, 1991, the Minnesota Department of Human Services announced new charges for the cost of care at regional treatment centers and state nursing homes, effective on that date. The new per diem charge for persons with mental retardation and related conditions in each of the eight regional treatment centers will be \$271.45.

Interim charges are calculated 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.

Source: *Instructional Bulletin #91-77A*, Minnesota Department of Human Services.

Editor's note: The population of people with mental retardation and related conditions residing in regional treatment centers has decreased from 1,438 in June 1989 to 1,177 in June 1991.

## STAR Program Publishes Two Free Brochures

1. *Assistive Technology and Home Modifications for Individuals with Disabilities*. This brochure provides strategies and resources for modifying homes to allow people with disabilities to live independently, safely, and with dignity. Criteria for these modifications, for every part of a typical home, are included.

2. *Consumer Products and Individuals with Disabilities*. This brochure provides some helpful hints for consumers with disabilities to think about before purchasing common products on the market. A checklist of questions to ask yourself before spending your money is provided as well as suggestions regarding product design, service contracts, maintenance, and where to get more information. Contact: STAR Program, 612/296-2771 (Voice), and 612/296-9962 (TDD).

## Henry from page 1

primary responsibilities included ensuring that counties found alternative community placements for children living in institutions. As a result of her work, the state institution population of children declined from 245 in 1980 to three in 1991. In addition to her work, Anne has served on the Governor's Planning Council on Developmental Disabilities.

This award was named for Bernard P. Becker, attorney, U.S. Magistrate, and long-time advocate for people who are poor and disadvantaged.

## The Three Dragons

by Marsha Forest and Jack Pearpoint

There are three dragons that prevent inclusion from happening.

The first dragon is **FEAR**. It is critical to name the fears and deal with them. All of us are afraid of the unknown, but instead of telling the fear like it is, we hide and blame others or say that something is impossible to do. But now we know that integration is possible. The data is in. The children will do just fine if we don't let our adult fears get in the way of progress.

The second dragon is **CONTROL**. As professionals we have to give up control and share power with those who have been in trouble. The first step is to invite those who have been left out to join us at the table. By asking the "problems" to be part of the solution, we are entering into powerful partnerships for change. We empower both ourselves and our new partners. Everyone wins in this scenario.

The third dragon is **CHANGE**. Change, though inevitable, scares us all. We fear it. We are always more comfortable with the status quo. We must make the change we want explicit, then face the fear, and give up the old controls that stop us from moving ahead.

In-service education and staff development must deal with the three dragons before building models of curriculum. Creative curriculum will flow when teachers leap over the three dragons and know that their jobs and futures are secure. Teachers need to fully understand **WHY** change is being made. If they **UNDERSTAND**, most will buy into the process with enthusiasm.

Once the three dragons are out in the open field, we can laugh and cry together over our fears. Then and only then, can we start to deal with teaching all kids to read, write, and be literate citizens in today's quickly changing and complex world.

Source: *Inclusion News* (Fall 1991), p. 3. *Inclusion News* is an occasional publication, available (with a voluntary donation) from: Centre for Inclusive Education & Community, 24 Thome Cresc., Toronto, Ontario, Canada M6H 2S. 416/658-5363

## Closing from page 1

"One size fits all" is a poor policy for selling pantyhose. Does it work any better in determining the housing needs of people with mental retardation? What ever happened to individualization? To normalization? What is it about being mentally retarded that makes adults want to live in groups of 12? How do clinical professionals justify such recommendations?

All too often policy decisions are made without a full appreciation that closing institutions is not an end in itself. The streets of every city in America are testimony to the barrenness of that policy. Closing institutions is good policy only if it opens the door to real possibilities of a normal life, with genuine choices and opportunities. It must offer more than a chance to ride the same van to be segregated with different people in different places.

In a very real way, the challenge and opportunity of closing institutions forces us to confront the question: for whose benefit are we doing this?

If we believe we are acting in the interests of the residents of the institution, don't reason and common sense suggest that we be solicitous of their needs and preferences and plan the development of services around the individual? How many people receiving 30, 40, or 50 thousand dollars per year would choose to buy a bed in an Intermediate Care Facility and live with 10 or 12 other adults and a staff they have no voice in choosing?

If the convenience of the moment allows us to discard the accumulated wisdom which led to laws requiring individualization, choice, normalization, we will act in haste and perhaps meet the deadlines of the moment, but spend the lifetimes of our clients repenting what we have done.

# Events

## August 10, 1991

Parent Case Management Summer Training Session will be held at the St. Cloud Holiday Inn, St. Cloud, MN. The workshop is designed to enable attendees to participate more fully in the case management of services for their children. Contact: Marijo McBride, Institute on Community Integration, 6 Pattee Hall, University of Minnesota, 150 Pillsbury Drive SE, Minneapolis, MN 55455. 612/624-4848.

## September 13, 1991

A conference on mental health issues of adults with brain injury and the impact on their families will be hosted by Courage Center, 3915 Golden Valley Road, Golden Valley. Sponsored by the Minnesota Head Injury Association and the Traumatic Brain Injury Program, and the Minnesota Department of Human Services, this conference is for professionals and others who work with adults with brain injury and their caregivers. Call: 612/520-0210.

## September 20-22, 1991

The National Down Syndrome Congress will hold its 19th Annual Convention, "Continue the Revolution," at the Boston Park Plaza Hotel & Towers, Boston, Massachusetts. Contact: NDSC, 1800 Dempster Street, Park Ridge, IL 60068-1146. Toll-free: 1/800/232-NDSC

## September 25-26, 1991

The Minnesota SILS Providers, Inc., providing a forum for Semi-Independent Living Service consumers, providers, and interested others, will hold a conference "Maximizing Potential" at the Holiday Inn in St. Cloud. Contact: Laura Lund at 612/870-0383.

## September 30-October 1, 1991

"Inclusive Education: Full Membership" workshop will be sponsored by Hopkins School District and Minneapolis Children's Medical Center at the Eisenhower Community Center, 1001 West Highway 7, Hopkins. Featured speakers: Marsha Forest and Jack Pearpoint. Call: Gay Rosenthal, 612/933-9236, or Tom Koch, 612/933-9270.

# Resources

*Together Successfully: Creating Recreational and Educational Programs that Integrate People with and without Disabilities*, John E. Rynders & Stuart J. Schleien, published by ARC United States, National Office of 4-H and Youth Development, and the University of Minnesota (1991). This handbook is filled with practical, step-by-step directions for creating activities that will virtually assure the success of an integrated recreation or education program. With the goal of promoting inclusive communities, this guide explains not only the "why" but, most importantly, the "how." Guides are provided for encouraging positive peer interaction, and how to avoid common problems or mistakes. A variety of activity plans and adaptive techniques can be used to meet individual needs and interests. Stories about several individuals and profiles of successful programs illustrate only some of the possibilities open to the imagination. A list of additional resources are provided in an appendix. Available for \$12.50, payable to: Association for Retarded Citizens of the United States, Publications Department, P.O. Box 1047, Arlington, TX 76004. Or, a copy may be borrowed from the Lending Library, as described on the back page of this newsletter.

# Resources *continued*

*Quality Assurance Resources: Instruments, Organizations, and Publications*, ARC United States (1989). This guide lists and describes a number of resources and methods for assessing and obtaining quality programs and services for persons with developmental disabilities. "Quality" is defined as multidimensional: 1) from the individual's satisfaction viewpoint; 2) from the satisfaction of other people who are closest to the person receiving services, such as friends and family members; 3) measures of outcomes, such as productivity, integration, or interdependence; 4) relevance and functionality of individual plans; 5) service coordination/case management; 6) citizen monitoring; and 7) licensing and certification. "Organizational commitment and actions toward quality actually lead to definition and redefinition of what constitutes quality," the authors state. Cost: \$4.00, payable to ARC United States, National Headquarters, P.O. Box 1047, Arlington, Texas 76004. 817/640-0204

*Augmentative Communication Publications*--The American Speech-Language Hearing Association has produced a number of helpful guides for assisting people who do not speak or write, but can communicate by using such devices as: communication boards, switches, symbols, adapted computers, and manual sign language. For example, a series of five booklets provide ideas and resources: Book 1--for General Public; Book 2--for Educators; Book 3--for Administrators; Book 4--for Medical Community, and Book 5--for Consumers; Another publication *Implementation Strategies* provides over 70 exemplary examples for implementing a comprehensive service delivery program. Contact: American Speech-Language Hearing Association 10801 Rockville Pike, Rockville, MD 20852. 301/897-5700.

## 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.

*Another Perfect Day* (videotape, 5 minutes), a parody on the field of services, can provide a humorous start to a serious discussion.

*Interview with Lou Brown*, (videotape, 47 minutes), April 1987, promotes supported employment of people with severe disabilities. "This really generated ideas at our training session," said one DAC Director.

*Partnership for Quality Services: Volunteer Monitor's Handbook* (publication and videotape, 24 minutes), Arc Minnesota, a project that illustrates how volunteers and professionals can work together to assure that people lead valued lives in the community.

*Together Successfully: Creating Recreational and Educational Programs that Integrate People with and without Disabilities.* (Publication). See description on page 3.

## Public Hearings on Assistive Technology Scheduled in August

The STAR Program is holding public hearings to determine, "What are the barriers preventing the use of assistive technologies by Minnesotans with disabilities?" Information is being collected for presentations to Congress regarding the reauthorization of the Technology-Related Assistance for Individuals with Disabilities Act and for continued funding in Minnesota. Call your local Hearings Coordinator to register, find out more about the meeting, and indicate if an interpreter or other accommodations are needed. The dates, towns, and coordinators are:

- August 6: Owatonna, Dave Williams, 507/451-5897
- August 8: St. Paul, Linda Koerner, 612/296-2771
- August 12: Duluth, Randy Vogt, 218/723-3809
- August 13: Hibbing, Bobbie Bouvier, 218/262-6675
- August 14: Thief River Falls, Peter Lavalier, 218/681-4949
- August 15: Moorhead, Marie Swanson, 218/236-2286
- August 20: St. Cloud, Glen Hoppe, 612/255-4913
- August 22: Worthington, Linda Ebner, 507/372-2983, or 507/831-4854

Additional written testimony may be submitted by August 30, 1991, to: Governor's Advisory Council on Technology for People with Disabilities, STAR Program, 300 Centennial Building, 658 Cedar Street, St. Paul, MN 55155. 612/296-2771

## Why No Paperwork Rebellion?

Every chance I get, I ask this question. One of the greatest sadnesses in my life has been the slow realization that we often prefer paperwork to working directly with consumers. I see no other reason. If we enjoyed the activities that paperwork keeps us from, we would be far more assertive and demanding in bringing the paperwork boondoggle to a halt, and instituting other mechanisms to carry out legitimate monitoring and review functions.

**Source:** John Shea, *Where's the Jello? The Continuing Saga of One Home's Experience with the ICF/MR (Small) Program* (1990). Available from Allen, Shea & Associates, 1040 Main Street, Suite 208, Napa, CA 94559. 707/258-1326

## 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

Governor's Planning Council on Developmental Disabilities

September 1991

## Illinois Study Concludes, 'Supported Employment Benefits All'

Unlike other research about supported employment, a three-year longitudinal study conducted by Corporate Alternatives, Inc. in Illinois measured individual growth and development of people working in supported employment settings and compared them with others who remained in traditional day programs. The researchers concluded that this study "yields undisputable evidence that supported employment benefits all parties involved."

The three-year study, funded by the Illinois Department of Rehabilitation Services, had two components--longitudinal and matched pair comparison. The longitudinal component followed 54 movers (persons in supported employment) over three years to determine level of adaptive behavior, challenging behavior, vocational skills, socialization skills, degree of integration in the workplace, and wages earned. For the matched pair comparison, 29 movers were matched with 29 stayers (persons who remained in traditional day programming), and noted the comparisons between the two groups in the same areas listed above. In addition, satisfaction with supported employment was studied in interviews with the people working in supported employment, employers, family members, and job coaches.

### The authors of the report concluded:

(This study) has shown that people with disabilities have greater opportunities for integration, their average earnings have tripled, and they have expressed 100 percent job satisfaction once moved to supported employment. Every one of the employers polled said based on this experience "they would hire more persons with disabilities." Families are pleased with their relatives' progress and job coaches are almost unanimous in expressing their satisfaction with their jobs despite low wages. Most importantly, people with disabilities themselves offer a glowing endorsement of the supported employment program.

The study substantiated observations made by the National Conference of State Legislatures' *Report of the Task Force on Developmental Disabilities*, that supported employment "is a cost effective alternative . . . and the benefits of supported employment are greater because gainfully employed people pay taxes, depend less on public programs, and contribute money to the state economy. Moreover, people who in the past were segregated can enjoy the same community benefits as do people without disabilities."

For further information about the *Three-Year Longitudinal Study of Supported Employment in Illinois*, contact: Cathy Huffman, Research Manager, Corporate Alternatives, Inc., 625 South College Street, Springfield, IL 62704. 217/544-5687

## Justice's Back Door

by Robert R. Williams

Twenty degrees on a Monday morning.

The marbled inscription read  
"Equal Justice Under the Law."

But the steep white stairs  
to Lady Justice's front doorstep  
told me differently.

A young black guard came up  
and said  
me and my kind could get in by going  
around back.

The wry smile on my face  
lost on him,

I silently turned myself around  
and headed up the windswept concrete  
incline  
until I came eye-to-eye  
with the automatic door.

One sign on it read  
"Handicapped Only."

The other sign said  
"Door not in Operation.  
Enter at Front Door Only."

Source: *In a Struggling Voice: The Selected Poems of Robert Williams* (1989), p. 34. Robert R. Williams is a Washington, D.C. poet and disability rights activist.

### Inside This Issue...

*Requests for proposals issued  
in areas of technology, respite  
care, crisis nurseries, and  
caregiver support.*

*Telephone Assistance Plan  
altered by Minnesota Legislature.*

# Crisis Nursery, Respite Care, and Caregiver Support Grants

The Minnesota Department of Human Services (DHS) has issued three requests for proposals:

- 1. Crisis Nurseries**—The Children's Services Division is soliciting proposals to develop two new crisis nursery programs, one in the Twin Cities Metropolitan Area and the other in Greater Minnesota. A total of \$85,000 will be available each year for the two programs over a three-year period. An additional \$5,000 per year is available for the development of a supportive parent-to-parent volunteer program. Proposals must be submitted no later than October 15, 1991. Contact: Becky Montgomery, Children's Services Division, 612/297-3634.
- 2. Respite Care**—The Long Term Care Management Division is soliciting proposals to develop foster respite care for children with disabilities. A total of \$200,000 is available to existing programs, and for the development of at least two new projects. Proposals are due October 15, 1991. Direct requests for RFP from Melody Nagy, 612/297-1698. For more information, call Nancy Smith, 612/296-5892.
- 3. Respite Care and Caregiver Support**—The Long Term Care Management Division is requesting proposals to establish up to 32 projects statewide to benefit informal caregivers. The total amount available for fiscal year 1992 is \$240,000, and for fiscal year 1992—\$640,000. Projects must serve at a minimum caregivers providing care to persons over age 65, and to other persons as resources allow. Contact: Nancy Smith, 612/296-5892.

The address for the Department of Human Services is 444 Lafayette Road, St. Paul, MN 55155.

# Events

**September 13, 1991**

"Putting the Pieces Together" is a conference that will explore mental health issues of adults with brain injuries and the impact on their families. Location: Courage Center. Contact: Ann C. Trelow, Courage Center, 3915 Golden Valley Road, Golden Valley, MN 55422. 612/520-0210.

**September 14, 1991**

Race Walk Classic for Autism, Fun Walk, and Junior Race Walk, will be sponsored by the Twin Cities Society for Children and Adults with Autism, Inc. at Phalen Park, St. Paul. If you wish to volunteer, call: Sara Struve, WalkSport America, 612/291-7138. Contact: Sue Minor, 612/535-4273.

**September 20-31, 1991**

Arc Minnesota will hold its Annual Conference, "Families: Building Blocks for the Community," at the Kahler Hotel in Rochester. Susan Stephani will keynote, "Living Life on Purpose." A.M. "Sandy" Keith, Chief Justice of the State Supreme Court, will present at the Conference Banquet. Contact: Arc Minnesota, 3225 Lyndale Avenue South, Minneapolis, MN 55404. 612/827-5641, or 1/800/582-5256, toll-free.

**September 21, 1991**

The Epilepsy League of Lake Superior will hold a conference, "Living with Epilepsy," at St. Luke's Hospital, 915 East 1st Street, Duluth. Contact: Epilepsy League of Lake Superior, 218/722-4526, or 1/800/637-1542 (if from AC 715 or 218).

**September 25-26, 1991**

"Maximizing Potential" is the theme of the Minnesota SILS Conference, sponsored by Minnesota SILS (Semi-Independent Living Services) Providers, and the Minnesota Governor's Planning Council on Developmental Disabilities, in cooperation with the North Central Technical Colleges. The conference will be held at the Holiday Inn, St. Cloud. Contact: North Central Technical College, 218/894-3726, or 1/800/247-6836, toll-free.

**October 5-6, 1991**

"We the Parents. . . Working as Agents for Change--Celebrating the Strengths of Our Families" is a statewide conference for parents of children with special needs hosted by PACER Center. It will be held at Sheraton Park Place, Minneapolis. Keynote: Anne Konnallen, University of Wisconsin--Madison. Contact: Casey Gorka or Heather Lyle at PACER 612/827-2966.

**October 7-8, 1991**

Minnesota Association for Guardianship and Conservatorship (MAGIC), will host "Standards Make the Difference" Conference at the St. Paul Hotel, St. Paul. Keynote: Gerald Provencal, Director, Macomb-Oakland Regional Center, Michigan. Contact: Lorna Wiens, North Central Technical College, Airport Road, Staples, MN 56479. 218/894-3726, or 1/800/247-6836, toll-free.

**October 15-18, 1991**

North American "Out-of Home Care Conference: Challenging the New Realities," will be hosted by the Child Welfare League of America Mid-West Region in St. Louis Missouri. Contact Child Welfare League of America, 440 First Street, NW, Suite 310, Washington, DC 20001-2085. 202/638-2952.

**October 17-19, 1991**

Closing the Gap Conference: Microcomputer Technology in Special Education and Rehabilitation will be held at Radisson South Hotel and Hotel Sofitel, Bloomington. Contact: Closing the Gap, 2000 West 98th Street, Minneapolis, MN 55431. 612/881-7811, or 1/800/222-7907.

## Resources

*Directory of Funding Resources for Assistive Technology in Minnesota*, STAR Program, 1991. This publication contains information about agencies and organizations in Minnesota that fund technology that can be used by persons with disabilities. By definition, an assistive technology device is any piece of equipment that is used to increase, maintain, or improve functional capabilities. The directory format helps to compare programs and tells how to get in touch with a number of resources. The information was compiled from returned questionnaires. Available from: STAR Program, 300 Centennial Office Building, 658 Cedar Street, St. Paul, MN 55155. 612/297-1552 (voice), 612/296-9962 (TDD)

*Inclusion*, Expectations Unlimited, Inc., 1991. This is a catalog of writings and recordings that reflect many new experiences and beliefs about the importance of including all children in school, and building inclusive communities. The recordings and printed materials can be used as tools for learners, teachers, and others for gaining greater insights about the human potential. Contact: Expectations Unlimited, Inc. P.O. Box 655, Niwot, CO 80544. 303/652-2727.

*From Behind the Piano: the Building of Judith Snow's Unique Circle of Friends*, Jack Pearpoint, Inclusion Press, 1990. This is a book about Judith Snow, Marsha Forest, Jack Pearpoint, and their friends. It is also the story of the genesis of the "Joshua Committee," that "knocked down the walls," and supported each member as true friends do. According to Robert Perske, "This is a grabber . . . the best story yet." Price: \$10.00, payable to Expectations Unlimited, Inc., P.O. Box 655, Niwot, CO 80544. 303/652-2727.

*Adult Protective Services: Practice Guide*, Minnesota Department of Human Services, 1991. Designed for practitioners in adult protection, this manual describes services in Minnesota as prescribed by law and regulation, human rights, and ethical practices. Guidelines are provided regarding people with special needs, such as: abuse and neglect of people who are elderly, or have a chronic illness or disability; self-neglect; victims of sexual assault; and people who are dying. Other sections cover family caretaking, cultural differences, and reaching a higher standard of practice. Contact: Adult Protection, Minnesota Department of Human Services, 444 Lafayette Road, St. Paul, Minnesota 55155.

## Technology Grants Announced

The STAR Program has issued four requests for proposals:

1. Community assistive technology resources to create new and expand existing programs. Total funds available: \$100,000, with an average grant between \$5,000 and \$25,000.
  2. Assistive technology mobile van delivery programs to improve devices and services. Level of funding: \$100,000.
  3. Research and writing of public education brochures to increase public awareness of the role of assistive technology devices and services in relation to disability and lifespan issues. Level of funding: \$10,000.
  4. Training curriculum coordination and delivery to expand local capacity through in-service training for professionals and employers. Level of funding: \$14,500.
- Deadlines: October 11, 1991**, for numbers 1 and 2; and **September 23, 1991**, for numbers 3 and 4, above.  
Contact: Rachel Wobschall, STAR Program, Department of Administration, 300 Centennial Office Building, 658 Cedar Street, St. Paul, MN 55155. 612/297-1552 (Voice); 612/296-9962 (TDD).

## Bruininks Named College Dean

Robert H. Bruininks, professor of educational psychology and director of the Institute on Community Integration at the University of Minnesota, has been appointed dean of the University's College of Education effective September 16, 1991. Bruininks has served on the faculty since 1968. In the mid-1970s, Bruininks served as executive director of the Governor's Planning Council on Developmental Disabilities. From 1981 to 1984, he was a Kellogg Foundation National Leadership Fellow, and just recently completed his term as president of the American Association on Mental Retardation. In 1985, under Bruininks leadership, the Institute on Community Integration was established as a University Affiliated Program, funded by the Administration on Developmental Disabilities. Congratulations Dr. Bruininks!

## 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.

**Respite Care is for Families: A Guide to Program Development,\*** CSR Inc., Washington, DC. This manual suggests how to design respite care services that are responsive to parent and family need.

**Respite Care: A Guide for Parents,\*** CSR Inc. Washington, DC. This booklet provides parents with information about the benefits of respite care, the ways in which respite care services are organized and funded, and strategies for finding and using respite care services in their communities.

**Letting Go: Views on Integration** (videotape, 19 minutes). Parents tell of the difficulties and risks involved as their children with disabilities experience the "real world."

**My Uncle Joe** (videotape, 15 minutes). A nephew's story about his uncle who is learning how to live independently after years of being institutionalized.

\*The publications about respite care are available for \$4.00 each, payable to CSR, Inc., Respite, Suite 600, 1400 Eye Street, NW, Washington, DC 20005. 202/842-7600.

## Legislature Makes Changes in Telephone Assistance Plan

Starting July 1, 1991, as a result of changes made by the Minnesota Legislature, new procedures for application and revised income eligibility requirements will become effective for the Telephone Assistance Plan (TAP). TAP provides assistance through a discount on the cost of local telephone service to persons who are at least 65 years of age, or have a disability, and who meet the income guidelines.

Minnesota law requires that to be income eligible for TAP, a household's yearly gross income must not exceed 150 percent of the federal poverty guidelines. The following new income limits were previously announced in the February 20, 1991, Federal Register:

\$ 9,930 Single person.

\$13,320 Married or single with child under 18 who lives with the subscriber.

\$ 3,390 Add for each additional minor child who lives with the subscriber.

The subscriber or spouse must first meet the elderly or disabled criterion. If they meet this criterion, they must then be within TAP income limits or receive public assistance. The receipt of public assistance alone does not qualify a person for TAP.

The Department of Human Services (DHS) will now determine eligibility for the TAP credit prior to receipt of the credit. Applications are available at county human service agencies. Applicants must now send the completed application directly to DHS rather than to their telephone company.

Questions should be directed to: The Telephone Assistance Plan, Department of Human Services, 444 Lafayette Road, St. Paul, MN 55155-3859. Metro area call: 612/296-2765. Toll free: 1/800/657-3838.

## Futurity

### DEPARTMENT OF ADMINISTRATION

Governor's Planning Council on  
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300 Centennial Office Building  
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# Futurity

October, 1991

Governor's Planning Council on Developmental Disabilities

## 'HOME,' Where People Find a Sense of Place, Control and Ownership: Developing an Agenda for Change by John O'Brien

The following thoughts are summarized from a paper written by John O'Brien, Responsive Systems Associates, entitled "Down Stairs That Are Never Your Own: Supporting People with Developmental Disabilities in Their Own Homes" (1991). A complete copy of the text may be requested by calling 612/296-4018, voice or 612/296-9962 TDD.

Most adults with developmental disabilities eat the bread of others and know only the way that goes up and down stairs that are never their own. Either they live in their parent's house or they occupy a bed in a place set up to offer supervision and treatment. Mostly, opportunities to hold one's own lease requires the ability to succeed with minimal assistance. Problems usually send a person in difficulty down the steps of the service continuum to a bed in a more restrictive facility.

Review of existing residential services reveals substantial limitations in the current standard, such as: rising costs, recruiting and retraining capable staff, and the energy it takes to comply with increasingly complex regulations. Structured programs may increase people's skills, but very few people graduate to independence, and even fewer achieve full community membership. Years of hard work have produced many settings that may be home-like, but most really seem much more like small facilities than like people's homes.

A growing number of people actively question the assumption implicit in the current standard. They notice that most debate and development continues to be focused on facilities. They ask why a need for personal assistance should bar people with severe disabilities from enjoying the benefits of life in their own homes. The new standard resonates with most people's desire for a home of their own, and there are an increasing number of stories about positive changes that result when people with severe disabilities have their own place. These experiences suggest an appealing alternative to the increasingly apparent limitations of facility based services.

The vision of people with severe disabilities living with support in their own homes contradicts most current policy and practice. A new agenda can be shaped by considering three dimensions of what it means for people to have their own homes: 1. they will experience a sense of place; 2. they or their agent will control their home and the support necessary to live there; and 3. through ownership, they will occupy a valued role with greater opportunities to build equity or credit ratings.


**SENSE OF PLACE:** People with a sense of place comfortably inhabit and personalize their home. They choose the ways they want to invest their time, skills, energy, and money in the routines of homemaking. They have the sense of personal security that comes from legally assured tenure. Many current practices deprive people with severe disabilities of a sense of place, such as: people's continued residence depends on compliance with the service providers' house rules and their compliance with requirements set by professional teams and

*"You will come to know  
how bitter as salt and  
stone is the bread of  
others, how hard the  
way that goes up and  
down stairs that are  
never your own."*

(Dante, Paradise, CANTO xvii, 58-60)

## New Director Appointed for Institute on Community Integration

Dr. Scott R. McConnell, Associate Professor of Educational Psychology at the University of Minnesota, has been appointed director of the Institute on Community Integration, a University Affiliated Program. McConnell replaces Robert Bruininks, who has been named dean of the University's College of Education. McConnell has extensive experience in the areas of research and practice in early intervention, social interaction skills training, and school psychology.



Inside This Issue...

*University awarded  
transition grant.*

*IBM computer discount program.*

*Expanded SSI eligibility for  
children.*

## **University of Minnesota Awarded National Transition Grant**

The Institute on Community Integration (UAP) at the University of Minnesota, has been awarded a \$175,000 grant to conduct a three-year national study on the transition of individuals with severe disabilities leaving school. The grant is provided by the National Institute on Disability and Rehabilitation Research, U.S. Department of Education. The study will be conducted in collaboration with the University of Illinois at Urbana-Champaign and the University of Vermont. The study will survey and evaluate 5 to 6 states to assess post-school outcomes; collect case studies to identify, document, and analyze information on exemplary transition policies, administrative practices, and funding strategies; develop a model policy and decision-making framework for state to use in formulating exemplary transition policies and practices; and disseminate information about the study. Contact: David R. Johnson, Institute on Community Integration, 109 Pattee Hall, 150 Pillsbury Drive, SE, Minneapolis, MN 55455. 612/624-4848.

## **ARC Minnesota Appoints New Executive Director**

Barbara W. Kaufman has been hired to fill the agency's Executive Director position, effective September 1, 1991. Ms. Kaufman has twenty-three years of experience in management, advocacy, and community organization in the field of human services in both the private and public sectors. Most recently, she was the Assistant Commissioner for Mental Health Services with the Minnesota Department of Human Services. The mission of ARC is to ensure the full participation of people with developmental disabilities in their communities by promoting systems of support and self-sufficiency for individuals and their families and by advocating for their rights. ARC has over 7,000 members in 54 chapters throughout Minnesota. Contact: Cindy Yess, President, 612/827-5642, or 1-800/582-5256, toll-free.

## **EVENTS:**

### **October 10-11, 1991**

"Creative Options for People with the Most Severe Disabilities" is the third annual training symposium sponsored by Minnesota Habilitation Coalition, Region X Developmental Service Providers, Albert Lea Technical College, and the Governor's Planning Council on Developmental Disabilities. Place: Sheraton Inn Airport, Bloomington. Keynote address: Bernard Carabello, Self-Advocacy Association of New York State. Other presenters include: Lou Brown, Ricardo Cerna, Chris Heimerl, Dana Henning, Wade Hitzing, Joel Jacobs, Frederick Kaeser, Herb Lovett, and Karen Green. Contact: Extended Campus, 2200 Tech Drive, Albert Lea, MN 56007. 507/373-333-2584, or 1-800/333-2584, toll-free.

### **October 17-19, 1991**

Closing the Gap Conference: Microcomputer Technology in Special Education and Rehabilitation will be held at Radisson South Hotel and Hotel Sofitel, Bloomington. Contact: Closing the Gap, 2000 West 98th Street, Minneapolis, Mn 55431. 612/881-7811, or 1/800-222-7907.

### **October 19, 1991 (7 to 10 pm.)**

Juke Box Saturday Night, a Metro-Wide dance will feature the KDWB party Music Machine and door prizes at the Richfield Community Center, 7000 Nicollet Avenue South, Richfield, MN. Proceeds will benefit programs used by persons with developmental disabilities who are living independently in the community. Sponsor: TRAIL (Transportation Resource to Aid Independent Living). Fee: \$5.00. Contact: Elaine Becker at 612/835-4736, or Nancy Booker at 612/835-1760.

### **October 24, 1991 (11 am. to 4 pm.)**

The Sixth Annual Job Success Fair will be held at the Bloomington National Guard Armory, 3000 West 98th Street, Bloomington, MN. This is an opportunity for matching employers and people with disabilities. Call: 612/887-9604, ext. 409 (voice), or 612/887-9677 (TDD).

### **October 25, 1991**

The Special Education Law Conference will be held at the Thunderbird Motel and Convention Center, Bloomington. Topics include global issues, access to neighborhood schools, attorney fees, extended school year, and the Americans with Disabilities Act. Contact: Educational Law Specialists, Inc. P.O. Box 8037, St. Paul, MN 55108. 612/633-2109.

### **November 1-2, 1991**

Family Unity Policy Forum is a retreat to develop family support policy in the state of Minnesota. It will be held at the Howard Johnson Hotel and Conference Center, 1201 West County Road E, Arden Hills. Contact: Jacki McCormack, Arc Ramsey, 425 Etna Street, suite 35, St. Paul, MN 55106. 612/778-1414.

### **November 6, 1991 (9 am. to 4 pm.)**

"Alternative Methods to Providing Case Management Services" is a meeting sponsored by the Association of Minnesota Counties, the Governor's Planning Council on Developmental Disabilities, and the Department of Human Services. The meeting will be held at the Holiday Inn, Shoreview. New legislation allows for alternative methods of providing case management services to persons with mental retardation and related conditions. For more information, contact the Governor's Planning Council on Developmental Disabilities, or call Ron Kaliszewski at 612/297-3207.

**November 8, 1991**

Courage Center and Hazelden will hold a conference on chemical use by people with physical disabilities, "Bridging the Gap: Identification and Therapeutic Approaches." Location: Courage Center, 3915 Golden Valley Road, Golden Valley, MN. Call: Ann Strelow, 612/520-0210.

## RESOURCES

**AN INTRODUCTION TO THE WHOLE COMMUNITY CATALOG**, Communitas, Inc., under sponsorship of the Connecticut Developmental Disabilities Council (1991). This publication provides a sample of what to expect next Spring, 1992, when the first edition of *The Whole Community Catalog* is scheduled for publication. This resource will follow the tradition established by Stewart Brand in the late sixties, when the idea of the *Whole Earth* catalog was born. Communitas has an international mission to share ideas, possibilities, and resources concerning the full inclusion of children and adults with disabilities into the community life. This introductory edition, published free of charge, contains a feature article by John McKnight, "John Deere and the Bereavement Counselor." Other content covers re-visioning: people, the community, ourselves, and our collective responsibilities. Other catalogs and networks are listed. Details are provided for ordering *The Whole Community Catalog*. Contact: The Whole Community Catalog, c/o Communitas, Inc., 185 Pine Street (#002), Manchester, Connecticut 06045.

**SPECIAL NEEDS, SPECIAL SOLUTIONS: How to get Quality Care for a Child with Special Health Needs: A Guide to Health Services and How to Pay for Them**, Georgianna Larson and Judith A. Kahn, Lifeline Press, 1991. This guide provides fundamental information needed by parents to obtain quality health care services for their children. Specifically, this book shows how to: 1. work with health care teams, 2. develop assertiveness skills, 3. explore public payment programs and utilize private health insurance options, 4. deal with stress and emotions, 5. handle issues/disagreements with health plans, 6. interpret terms used by health providers and insurers, and 7. get help from books, national organizations and agencies. Price: \$7.95. Contact: Lifeline Press, 2500 University Avenue West, St. Paul, MN 55114. 612/659-9114. (A copy may also be borrowed from the Lending Library, details on the last page).

## Introduction to Autism Classes

The Twin Cities Society for Children and Adults with Autism, Inc. will be holding its **Introduction to Autism** class at their office four times this fall. The three-hour class starts at 6:30 pm and will be offered on October 22 and 30, as well as November 12 and 19. Fee: \$20.00. contact: TCSAC, 253 East Fourth Street, St. Paul, MN. Call Nancy Kobilka at 612/228-9074, or Bill Funario at 612/439-6247.

## Parent Classes on Cleft Palate

The Minnesota Department of Health will hold five, free informational meetings for parents on how to help teach their children with cleft palate to develop good speech and language. Different topics will be covered each session. Classes are scheduled for Mondays October 14, 21 and November 4, 11, 18, 1991 beginning at 7:00 pm. Location: Room L-100 (basement) at United/St. Paul Children's Hospital at 345 Smith Avenue North, St. Paul, MN. Contact: Donna Medin, Speech Pathologist, at 612/623-5174 to register.

## IBM computer Discount Program Offered at Courage Center

People with disabilities may purchase selected IBM personal computing products at a 30 to 50 percent discount and receive one-on-one assistance before and after the sale. The Computer Discount Program is a joint program with IBM and Courage Center at Golden Valley. The purpose is to help people gain access to computers for rehabilitative and therapeutic needs. Courage Center helps people decide what type of computer or adaptive equipment is needed, then they will provide assistance in ordering, system testing, equipment delivery, initial training, and telephone technical support. Call: 1-800/426-2133 (USA-Voice), or 1-800/284-9482 (USA-TDD). Write: IBM National Support Center for Persons with Disabilities, P.O. Box 2150, Atlanta, GA 30301-2150.

## Supreme Court Expands SSI Eligibility for Children

The number of children with disabilities who may qualify for receiving additional income from the Supplemental Security Income (SSI) has been expanded by a ruling from the Supreme Court. The Court ruled that in deciding whether a child is disabled, Social Security must consider the ability of the child to do "age appropriate activities." Being eligible for SSI means monthly cash payments, and possible eligibility to Medicaid for help with medical, dental, and hospital bills. The important message is for parents to contact Social Security at a new toll-free number to see if their child qualifies for SSI payments: 1-800/772-1213.

## Parents Wanted for Focus Groups

The Institute on Community Integration, University of Minnesota, is conducting focus groups on self-determination. It is seeking parents of students (ages 15-18) with moderate-severe disabilities. Each participant will be paid \$10. Call Denise Mumma at 612/550-7300. Leave your name, phone and best times for her to return your call.

## 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.

***The Parent Training Guide to Recreation***, National Parent Network on Disabilities (1991). (Packet: publication and videotape). Developed at the University of North Carolina at Chapel Hill, this is a complete training packet for use with parents in a planned training session. It includes the videotape, "Can Molly Come Out and Play?"

***Special Needs, Special Solutions: How to Get Quality Care for a Child with Special Health Needs***. (Publication). See page three for description.

***From Behind the Piano: The Building of Judith Snow's Unique Circle of Friends***, Jack Pearpoint, Inclusion Press, 1990. (Publication). This true story of friendship building highlights the importance of interdependence in society.

***It's About Learning: A Student Centered Approach to Adult Learning***, Marsha Forest with Bruce Kappel, Frontier College, 1988. (Publication). At Frontier College in Canada, literacy is the window to the community. Its central curriculum deals with the real issues in people's lives. The College is in the business of building community.

## 'HOME,' Continued from page one:

welfare policies. Indeed, if a service provider fails to comply with service system regulations, people with disabilities risk loss of their place to stay.

**CONTROL:** People have control of their homes when they have a choice of the place that they live and a choice of the people they live with. Many existing service practices deny people control of their own homes. Size of household is typically set by policy or by service provider judgements regarding the number necessary for economic viability. The people who happen to live together in a facility, and often the people who share a bedroom, are more likely to be selected by the accident of who happened to be eligible for a vacant bed than by mutual agreement or interest among those who live together.

**OWNERSHIP OR TENANCY:** Many peoples' pride of ownership reflects the fulfillment of a personal dream and frequently motivates efforts to improve and personalize property and strengthen the local social fabric. However, many people with severe disabilities cannot even establish tenancy.

State and federal disability policies must influence the extent to which people with severe disabilities can control their own homes. Policymakers who want to support people with severe disabilities to be at home will challenge and change two damaging assumptions: 1. residents of facilities deserve higher levels of per-person expenditure than people with their own homes; and 2. people who rely on public funds for necessary assistance must be passive and grateful recipients of professional control.

Those who want to assist people with severe disabilities to enjoy the benefits of tenancy and ownership will work on three fronts:

1. they will separate support services from facilities;
2. they will devise ways to increase material resources at people's disposal; and
3. they will seek out and create a variety of public and civic approaches to insure a decent standard of affordable housing.

These thoughts are best summarized in a statement made by Connie Martinez, a leader in Capitol People first of Sacramento, about the first bread that she baked,

*"That was the best bread I ever ate because that bread was the bread of my knowledge."*

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Roger Strand, Editor  
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