

# Futurity

Governor's Planning Council on Developmental Disabilities



January 1992

## Harris Poll Supports Inclusion of People with Disabilities

A recent Louis Harris and Associates poll, *Public Attitudes toward People with Disabilities (1991)*, shows that the majority of American people support increased participation of this nation's 43 million citizens with disabilities in community life. Harris **described** this study as "one of the most interesting and most important surveys my **firm** has ever **conducted**."

Movies and television programs apparently have had a powerful and positive impact **on** improving public attitudes toward people with disabilities. Individuals cited *Rainman*, *My Left Foot*, *Born on the Fourth of July*, and *Children of a Lesser God*, as **well** as television programs such as *LA. Law*, and *Life Goes On* as having had a very positive impact.

### Public poll highlights:

- **98** percent believe that everyone, including people with disabilities, should have equal opportunity to participate in American society;
- **92** percent believed that society will benefit economically if people with disabilities are fully assimilated as participating partners;
- **Nine** out of ten said that society will benefit from having persons with disabilities becoming more productive and contributing to the economy rather than receiving welfare payments;
- **Most** Americans have not yet heard of the Americans with Disabilities Act of 1990, but they overwhelmingly support its key provisions when informed;
- **96** percent support making public places, such as stores, restaurants, theaters, and hotels, accessible;
- **Almost half** **polled** know people with disabilities as friends, relatives, neighbors, or workers, and almost a third have a close friend or relative with a disability.
- **On the other hand**, most **Americans** continue to still feel somewhat awkward, embarrassed or apathetic around people with disabilities. **Seventy-seven percent said that they feel pity toward people with disabilities.**

Copies of the report are available for \$25.00, payable to: National Organization on Disabilities, 910 16th Street, NW, Suite 600, Washington, DC 20006. 202/293-5960.

[Source: United Cerebral Palsy Associations, *Word from Washington*, September-November 1991, pp. 28-29.]

## Equal Access is 'Good Business'

"Providing equal access is more than good sense, it's good business," said Hank Todd, **director** of the Minnesota Office of Tourism (MOT). This office is planning to educate those in the Minnesota tourism industry on the obligations and marketing advantages of meeting the requirements of the **Americans** with Disabilities Act. MOT is cooperating with the Minnesota State Council on Disabilities by offering **seminars**, educational materials, and a videotape on providing services to travelers with disabilities. Most of the public accommodations requirements will become effective on January 26, 1992. [Source: *Minnesota Enterprise*, Department of Trade and Economic Development, September 1991.]

*If all my possessions were taken from me with one exception, I would choose to keep the power of communication, for by it I would soon gain all the rest.*

**Daniel Webster**

### Inside This Issue...

*Facilitated Communication--  
New Challenges and Hopes*

*Health Resources for Youth*

*Parent Case Management  
Facilitator Training*

## Resources On

### Facilitated Communication

● Workshops on **facilitated** communication are scheduled for January 27 and 28, 1992 and May 11 and 12, 1992 in Syracuse, New York. Contact: Syracuse University, Division of **Special** Education and Rehabilitation, 805 South **Crouse** Avenue, Syracuse, New York 13244-2280. 315/443-5836.

• "**Communication** Unbound," Douglas **Biklen's** article in *Harvard Educational Review*, is available for \$3.25.

● A videotape, "I'm not Autistic on the **Typewriter**" is also available for **\$25.00**.

Another videotape of "Annegret **Shubert's** Workshop Presentation" is available for \$100.00.

• **Facilitated** Communication Resource Guide, is a 3-ring binder with a compilation of information. Price: \$16.00.

Order the article, videotapes, and guide from: **Adriana Foundation** 2001 Beacon Street, Room 214, **Brookline**, Massachusetts 02146. 617/232-8550, or 617/232-8634.

● A poster is available that reads: **NOT BEING ABLE TO SPEAK IS NOT THE SAME AS NOT HAVING ANYTHING TO SAY.**

This quotation was originated by Rosemary **Crossley**, educator and founder of the **DEAL** Communication **Centre** in Melbourne, Australia. Cost: \$6.00, plus \$2.00 postage/handling, payable to: Human Policy Press, P.O. Box 127, Syracuse, NY 13210.

### Newsletter for People with Hearing and Vision Loss

FIND, Inc. is now publishing a newsletter entitled, *Signals*. This free, monthly publication was developed to meet the needs of those with hearing and vision loss.

The newsletter is available in regular, large print, and Braille. FIND'S Information and Referral Project is funded by **Minnesota** State Services for the Blind. **Contact:** Mary Jo Spotts, FIND, Inc., 119 4th Street, N., Suite 308, Minneapolis, MN 55401. 612/333-3009 (Metro: **V/TDD**); or **1/800/944-2139** (Grater MN: **V/TDD**).

## Facilitated Communication: Old Theories Challenged, New Hopes Generated

When asked by the editor of *The Advocate* (Newsletter of the Autism Society of America, Spring 1991), "How did you become interested in facilitated communication?" Douglas **Biklen**, professor and director of special education at Syracuse University, replied, "It was **almost accidental**." He had read Rosemary **Crossley's** book, *Annie's Coming Out*, which **told** about her initial use of facilitated communication with people with cerebral palsy in Australia, but had paid no heed to her work **until** he visited her in Australia and observed students with autism. "I knew that I had observed something **extraordinarily important**, and came back knowing that I not **only** had to write about what I had seen, but also had to do the same thing here. His accounts **were published** in the *Harvard Educational Review* (August 1990).

Facilitated communication is a means of "facilitating" expression by people who either do not talk or do not **talk clearly**. In January 1989, **Biklen** began to use the method in Syracuse schools and community settings with students labeled autistic, ranging in age from three years nine months to 25 years old. **All** the students did not speak or had speech comprised of echoes. Most of them had previously been presumed to have intellectual disabilities.

With facilitation, students learn to point to letters and thus construct words, phrases, and sentences. The method involves initial hand-over-hand and/or arm support, pulling the hand back after each selection, slowing down the movements, assistance in isolating the index finger, verbal reassurances, and encouragement. Over time, the physical support can be faded back completely, or to **just** a hand on the shoulder.

**Biklen** and his staff began to "have success **with** the initial" **student**, immediately. They were quickly able **to** produce natural language through their typing, showing unexpected literacy and numerical skills. "**Almost** every day and certainly **every** week there were new students who were found to have the literacy skills and be able to communicate. We worked in the context of disbelief," **Biklen** exclaimed.

**Biklen** concluded his interview by saying: "I think the most important issue is that **we** are seeing that much of how we see students present themselves is a figment of the physical difficulties that they have and we have seen them as metaphorical, that is we have seen the physical behavior and **we** attributed a cognitive cause without evidence that there is a link. It's only as we've worked with a lot of students that **it** keeps hitting us. We should have seen this years ago because we **always** had little **pieces** of evidence that didn't fit. Now we see that they do fit, but they fit a different theory. We kept trying to explain away these islands of ability in an otherwise unable person. We would look at students and they knew who they wanted to relate to, we should have noticed that. Now we're seeing so much more because we have this new approach."

### in Touch, Inc., Expands Employment Opportunities

"Community Employment Opportunities" is a new alternative to traditional day training and **habilitation** programs for adults with disabilities (including individuals who are deaf, blind, or have communication difficulties). Hosted by Dakota County for the Twin Cities metro area, this **nonfacility-based** program provides job development coaching, and adaptations. Emphasis is placed upon having a total community experience--establishing friendships and **utilizin**g leisure and **recreational** resources. Referrals must be **placed** through county **social workers**. For more information, call: 612/342-2066 (Voice and **TDD**).

# Events

## January 21, 1992

"Healthy Roots--A Follow-Up Conference," at **Earle** Brown Continuing Education Center, University of Minnesota--St. Paul Campus. This continues discussions from March 1991 working conference relating to alcohol related birth defects. Sponsor: Maternal and Child Health, School of Public Health. Contact: Professional Development and Conference Services, 235 **Nolte** Center, 315 Pillsbury Drive, SE, University of Minnesota, Minneapolis, MN 55455-0139.

## January 23, 1992

"Motivating and Empowering People: Catalysts for Growth," is a workshop for managers and supervisors, led by Glen Werner, Psychologist, at Cambridge Regional Human Services Center, Main Building Conference Room C, Cambridge, MN 55008. Fee: \$25.00. 612/689-2121, ext. 502.

## February 24, 1992

"Aging--Enhancing the Journey" is the theme of the Minnesota State Chapter of the American **Association** on Mental Retardation (**AAMR**) conference to be held at the Minneapolis Metrodome Hilton. Contact: Bill Everett, 1918 19th Avenue, NE, Minneapolis, MN 55418. 612/789-8841.

# Mark Your 1992 Calendars

**April 1-3, 1992:** "Children '92: It's Up to You," Child Welfare League of America National Conference, Grand Hyatt Washington, Washington, **D.C.** **Contact:** **CWLA**, 440 First Street, NW, Suite 310, Washington, DC 20001. 202/638-2952.

**April 2-4, 1992:** Annual Minnesota Speech-Language-Hearing Association Convention at Duluth Entertainment Convention Center. Contact: John T. Hatten, University of Minnesota, Duluth, Minnesota 55812. **218/726-8205.**

**May 11-12, 1992:** Annual Syracuse Conference on Facilitated Communication, Sheraton University Inn, Syracuse, NY. Contact: Diane Briggs, School of Education, Office of Professional Development, Syracuse University, 250 Huntington Hall, Syracuse, NY 13244-2340. 315/443-5836.

**June 13-19, 1992** National Convention of the Deaf-Blind, **Macalester** College, St. Paul. **Contact:** MDBA, c/o In Touch, Inc. 1111 Third Avenue South, Suite 30, **Minneapolis, MN** 55404. (612) 342-2066.

**July 6-17, 1992:** Summer Institute in Integrated Education and Community: An innovative two-week immersion focusing on strategies for the integration of people with **challenging** needs into schools and community. Sponsors: McGill University and G. **Allan** Roehrer Institute. Location: McGill University, Montreal, Quebec. Contact: Marsha **Forest, Centre** for Integrated Education, 24 Theme **Cresec.**, Toronto, Ontario, Canada M6H 2S5. 514/3984242.

## Apply **Now** To Become A Facilitator in Parent Case Management Training

In an effort to provide assistance to a greater number of individuals and families, the Institute on Community Integration at the University of Minnesota is offering training and technical **assistance** to persons interested in becoming Parent Case Management Facilitators. one-day facilitator training **sessions** will be held during April and May at sites in northern, central, and southern Minnesota. Facilitators will **receive a** Resource Guide, Facilitator's Guide, handouts and a newsletter subscription. They will also receive technical assistance while implementing training for family members in their communities. A stipend of \$100.00 is offered to support their role. Applications are due by January 31, 1992. Contact: **Marijo** McBride, Program Coordinator, Institute on Community Integration, **University of Minnesota**, 103 **Pattee Hall**, 150 Pillsbury Drive, SE, **Minneapolis**, Minnesota 55455. 612/624-6830, 612/457-8138, or 612/624-7003 (**TDD only**).

## Adolescent Health Resources Support Transition to Adulthood

"Speak Up for Health" is a project at PACER Center that prepares young **people** with chronic **illnesses** and disabilities to become as independent as possible in meeting their own **health** care needs. Free packets of information are available to parents **and** their sons or **daughters**. (Cost to professionals is \$10.00). Topics include, health care skills, sexuality, and "letting go," as examples. Training workshops are scheduled on a variety of topics. In addition, information may be obtained by telephone relating to financing health care, and locating health resources. **Contact:** Speak Up for Health, PACER Center, 4826 Chicago Avenue, South, Minneapolis, MN 55417-1055. 612/827-2966.

## Lending Library

The following publications are available for a three-week loan. The only cost to the borrower is the return postage.

**Job-Match: A Process for Interviewing and Hiring Qualified Handicapped Individuals** (sic.), Ruth Bragman and Joyce Couch Cole, American Society for Personnel Administration, 1984. This book attempts to allay various myths and misconceptions about persons with disabilities and provides interviewers with "how-to" information.

**Packet: Labor Unions and Disability: Suggestions for Expanding Employment for Persons with Disabilities**, Employment Related Services Associates, 1990. Three booklets serve as guides on how the passage of the Americans with Disabilities Act represents both challenge and opportunity for organized labor; es advocates of worker rights and as partners with management in addressing those rights. Book #1: "A Manual for Labor Organizations and Their Members." Book #2: "Guidelines for Employment Specialists." Book #3: "Guidelines for Labor Unions and Their Members."

Purchase reformation: *Labor Union Packet* is available for \$7.00, payable to: Employment Related Services Associates, 12327 Golden Oak Circle, Hudson, Florida 34669. 813/856-6543.

## Resolutions... A Successful/Happy 1992!

**Anytime** art organization, **department**, or even an individual takes on the task of review, analysis, and improvement, it implies change. Change causes stress. Some people react or adapt to stress more easily than others. **There** can be no stress-less change. Our comfort zone (status quo) is the place where we understand the **rules** and what is expected of us. Change, or even the expectation of change, can and does cause: fear, confusion, disorientation, defensiveness, physical illness, uncertainty, guilt, anger, retreat, and apathy. Individuals and groups go through predictable cycles in reaction to forces that push them out of their comfort zone. The cycle starts with the status quo, where things are balanced, predictable, and stable. Discontent forces unbalance. What usually follows are, denial and confusion. What must occur to achieve successful resolution in the cycle are: communication, inspiration, ending with implementation.

Communication and inspiration are critical to the process. Communication means talking openly about the facts of the current situation and how people feel about the facts. In communicating, we are not trying to hide or ignore all the emotionalism of the discontent, denial, and confusion. Communication can define a problem or opportunity but it cannot create a solution, Finding a solution **requires--** inspiration. To achieve inspiration requires leadership energy.

### The following quotations are helpful:

**I am convinced that if the rate of change inside an institution is less than the rate of change outside, the end is in sight.**

**John F. Welsch, Chairman and CEO, General Electric.**

**If you want to truly understand something, try to change it.**

**Kurt Lewin.**

**Restlessness and discontent are the first necessities of progress.**

**Thomas A. Edison**

**The World that we have made, as a result of the level of thinking we have done thus far, creates problems that we cannot solve at the same level at which we created them.**

**Albert Einstein.**

**A person can succeed at almost anything for which they have unlimited enthusiasm.**

**Anonymous.**

[Swine: The American Public Power Association Performance Improvement Program.]

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DEPARTMENT OF ADMINISTRATION

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TIME DATED MATERIAL

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## Disability Perspectives on Health Care Reform Presented to Congress

On October 24, 1991, the Health Task Force of the Consortium for Citizens with Disabilities (CCD) presented testimony before the Ways and Means Committee of the U.S. House of Representatives on the subject of "Principles for Health Care Reform from a Disability Perspective." Following are some selected excerpts from this testimony:

When one considers the numbers (43 million people) and range of individuals covered by the definition of disability, it is no wonder that the issue of access to appropriate, adequate, and affordable health care and related support systems is of such critical importance. When considering the issue of health from the disability perspective, it is essential to refocus our conception of what being "healthy" really is. For so many people with disabilities, health is determined by functional capacity. It is the ability to maintain or "increase this functional capacity that is often the measure of the person with disabilities opportunity to live an independent life and participate as fully as possible in the life of the community. (We believe) that any effort to reform the nation's health care system must be built on five basic principles:

**Non-discrimination:** People with disabilities of "all ages and their families must be able to fully participate in the nation's health care system.

**Comprehensiveness:** People with disabilities and their families must have access to a health care system that ensures a comprehensive array of health, rehabilitation, personal, and support services across all service categories and sites of service delivery.

**Appropriateness:** People with disabilities and their families must be assured that comprehensive health, rehabilitation, personal, and support services are provided on the basis of individual need, preference, and choice.

**Equity:** People with disabilities and their families must be ensured equitable participation in the nation's health care system and not burdened with disproportionate costs.

**Efficiency:** People with disabilities and their families must have access to a health care system that provides a maximum of appropriate effective quality services with a minimum of administrative waste.

The CCD strongly supports the right to health care for all persons regardless of income or health status.

## Conclusion

The disability community needs to be a major player in reexamining health care financing policy. People with disabilities are highly vulnerable to the limitations of both public and private systems as they are squeezed between a private system which is designed to charge according to an assessment of risk and a public system which subsidizes health care according to age, poverty, status, family structure, and an inability to work.

Private health insurance was developed and has remained a method for spreading risk of incurring excessive costs primarily for hospital and physician services. For individuals with disabilities, access to health care has been severely restricted because of preexisting conditions

Continued on page three

"I worry . . . whoever thought up the term 'quality control' thought if we didn't control it, it would get out of hand."

-*The Search for Signs of Intelligent Life in the Universe*, by Jane Wagner, performed by Lily Tomlin.

## Your Brother's Face

An old Indian chief was standing night watch with his young braves. The braves asked the chief how they would know when the night was over and the dawn had fully broken. "Can we be sure night is over," they asked, "when we can tell the difference between a cow and a sheep on that hill over there?"

"No," said the chief.

"Will we know the night is over when we can see the color of the bird on the branch of a tall tree?"

"No," he said.

"Well, then, how can we know?"

"The chief answered, "You will know that the night is over when you look into the face of the man next to you and see your brother."

**Source:** *Reflections on Inclusive Education*, by Patrick Mckan, edited by Jack Pearpoint and Marsha Forest, Inclusion Press, 1991. To purchase a copy, send \$12.00 payable to: Inclusion Press, 24 Thome Crescent, Toronto, Ontario M6H 2S5; Canada. 413/658-5363.



## Inside This Issue...

*How to order federal laws.*

*Training for employers about Americans with Disabilities Act*

*Seattle designs action plan to support families.*

## FIND Offers Community Integration Services

Functional Independence Training, Inc., (FIND) is expanding community integration services throughout the state for **adults** and **children** with hearing and vision loss. Learn how to gain access to and participate in community events. Individual and group experiences and supports enhance integrated opportunities. Contact: Mary Jo Spotts, FIND, Inc., 119 4th Street North, Suite 308, Minneapolis, MN 55401, 612/333-9102 (voice and TDD).

## Summer Jobs for Youth with Hearing Impairment

The Minnesota Conservation Corps, Department of Natural Resources, will provide job opportunities this summer in **natural** resource work for youth who are deaf or have hearing impairments, **ages** 15 to 18. Corps members are paid \$4.25 per hour with room and board. Starting **June** 21, 1992, the Summer Youth Program will operate for eight **weeks** at the large residential camp at St. Croix State Park **located** near **Hinckley**. **Contact:** Peter M. Hark, Program **Coordinator**, Minnesota Conservation Corps, 500 Lafayette Road, St. Paul, MN 55155-4004. 612/296-2144 (voice and TDD).

## Job Analysis Training for Employers Offered

“Job **Analysis and Job Descriptions--** Meeting the Requirements of the Americans with Disabilities Act” is a one-day workshop for employers sponsored by Employer Education Service, Industrial Relations Center, **at the** University of Minnesota. Sessions are scheduled for February 13, March 2, April 9, May 5, and June 2, 1992, at the Hubert H. Humphrey Center, University of Minnesota, Minneapolis. **Contact:** Employer Education Service, 430 Management and Economics Building, 271 19th Avenue South, University of Minnesota, Minneapolis, MN 55455. 612/624-5525, or 1/800/333-3378.

## Seattle Envisions 'Family Support Opportunities for Action'

**Seattle, Washington:** **Seattle's** attempt to think broadly about families represents a **growing** understanding across the country that local governments have a stake in family well-being and a vast array of options to choose from in their endeavor to support families' development.

Over the past year, staff representatives from fifteen **government** departments and offices have worked together as the City of Seattle's Family Support Team to fashion a tool that would guide the City's discussion of family support issues. Beginning with a set of operating principles based on the values associated with the family support movement, the Team created a document which identifies the potential actions **local** government can take to support families, **called** *Family Support Opportunities for Action*. It includes broad goals, provides a definition of families, and identifies different **roles** the City can play.

“**Family**” is inclusively defined as, “a self-defined group of people who may live together on a regular basis and who have a close, long-term, committed relationship and share or are responsible for the common necessities of life. Family members may include adult partners, dependent elders, or children, as well as people related by blood or marriage.” The definition is included in a set of operating principles which encompass **empowerment**, a focus on prevention and early intervention, removal of barriers to service, the **importance** of cultural diversity, and participation of family members in planning and service delivery.

**Goals:** The City shall focus its energy and efforts to improve the **quality** of life, making Seattle the best possible place for families of all economic levels to **live**, and shall **strengthen** its capacity to support a **diverse** array of families and individuals.

1. Promote physically and emotionally healthy families.
2. Assure that families living within our community **can** meet their basic needs and receive the support necessary to be self-sufficient.
3. **Assure** a safe environment throughout **Seattle** for families.
4. Develop opportunities for families to live, work, play, and grow together in a multi-cultural environment that supports and promotes communication among all **groups** and individuals.
5. Work to attract and keep a diverse population in **Seattle**, which includes families with children, to ensure the city is a viable, dynamic community in the **future**.
6. **Promote** diversity within **Seattle's** neighborhoods and support neighborhoods that **are** economically, ethnically, and culturally varied.
7. Educate the public, including youth and families and elders, on the changing needs of families.
8. **Promote** partnerships within the community to meet the diverse and changing needs of families.

“This begins the process of building a collective awareness about and a more unified approach to family support and development” said Dawn Hanson Smart, senior **planner** in the City of Seattle's **Human Services Strategic Planning Office**.

Copies of the working document may be obtained by writing or calling: City of Seattle, Human Services Strategic **Planning Office**, 618 2nd Avenue, Room 1350, Seattle, WA 98104. 206/684-8057.

**Source:** “A City Grapples with Family Support: Seattle's “Family Support Opportunities for Action,” *Family Resource Coalition Report*, Vol. 10, No. 2., 1991, PP.10-11.

## Publications

**Awareness is the First Step Towards Change: Tips for Disability Awareness**, National Easter Seal Society, is 'a handy reference brochure covering myths and facts, proper etiquette and courtesies, and convectional tips. Available from National Easter Seal Society, 70 East Lake Street, Chicago, Illinois 60601. 312/726-6200 (voice), 312/726-4258 (TDD).

**Breaking Ground: Ten Families Building Opportunities through Integration**, C.B. Schaffner and B.E. Buswell, PEAK Parent Center, Inc., 1989. This book contains, stories often families who have begun "the journey toward full school and community inclusion for their children. The authors note, "When children are integrated, their disabilities often appear less significant because in integrated environments it's much easier to focus on a child's gifts and capacities." Robert Perske commented, "Without a doubt, these stories will get hundreds of families in similar situations dreaming about what they might do." Price: \$10.00. Payable to: PEAK Parent Center, Inc., Integration Project, 6055 Lehman Drive, Suite, 101, Colorado Springs, CO 80918. Also available on loan from the Lending Library; seepage 4.

**Living Skills: A Guide to Independence for Individuals with Deaf-Blindness**, FIND, Inc., (1991). This book is about independence for people who have difficulty seeing and hearing. These guidelines are intended to assist professionals, persons with deaf-blindness, and family members in determining an approach to learning and developing living skills. Content includes: an introduction to deaf-blindness, communication challenges, individual profiles, and independent skills (food and nutrition, home care, personal care, money management, and communication. Purchase price: \$30.00, plus \$3.90 postage and handling, payable to FIND, Inc., 119 North 4th Street, Suite 308, Minneapolis, MN 55401. 1(800)944-2139.

Note: Also available on loan through Lending Library; seepage 4.

## Perspectives: From page one

and the mistaken assumption that most people with disabilities need more hospital and physician care than the population as a whole. Health care reform needs to eliminate this restriction and assure access to needed hospital and physician services. Equally as important, the tradition of limiting covered services to hospital and physician services must be changed. Rehabilitation services, personal and support services, mental health services, and assistive technology must be recognized as essential components of health care.

Perhaps our greatest contribution will be in clarifying the principles which should guide our health care system. These include: (1) expanding the definition of "health" to include prevention services, rehabilitation therapies, assistive technology, and on-going health-related maintenance services; (2) distributing all health related expenses equitably throughout the population; and (3) restructuring our health care delivery system to more effectively support consumer-directed chronic care management.

For more information, contact any of the CCD Health Task Force Co-chairs:  
**Bob Griss**, United Cerebral Palsy Associations, 1522 K Street, N. W., Suite 1112, Washington, DC 20005. 202/842-1266.

**Kathy McGinley**, The Arc, 1522 K Street, N. W., Suite 516 Washington, DC 20005 202/785-3388.

**Bill Schmidt**, Epilepsy Foundation of America, 4351 Garden City Drive, Landover, Maryland 20785. 301/459-3700;

## EVENTS

### February 10, 1992 (6:30 p.m. to 9:30 p.m.)

"Parent Advocacy Workshop: Educational Rights," sponsored by PACER Center at will beheld at Hope Presbyterian Church, 7132 Portland Avenue South, Richfield. Call: 612/827-2966.

### February 20, 1992 (7pm. to 10 p.m.)

"Workshop for Parents on Adolescent Sexuality," sponsored by PACER Center, will be held at the Best Western Kelly Xnn, 161 St. Anthony, St. Paul, Minnesota. Contact: PACER Center, 4826 Chicago Avenue South, Minneapolis, MN 55417-1055. 612/827-2966 (voice and TDD).

### March 28-30, 1992

"Building on Family Strengths: A National Conference on Case Management for Children with Emotional, Behavioral, or Mental Disorders" will beheld in Portland, Oregon, at the Red Lion Hotel in the Lloyd Center. Contact: Research and Training Center on Family Support and Children's Mental Health, Regional Research Institute for Human Services, Portland State University, P.O. Box 751, Portland, OR 97207-0751. 503/725-4040.

### April 10, 1992

"Best Practices in Integrated Recreation," will address issues raised by the Americans with Disabilities Act, co-sponsored by the Division of Recreation, Park, and Leisure Studies, the Institute on Community Integration at the University of Minnesota, and the Minnesota Recreation and Park Association. Location: Earle Brown Center, University of Minnesota--St. Paul Campus. Call: Therapeutic Recreation Grant Project Office at 612/625-7583.

### April 23-24, 1992

"Creating a Sales Culture for Supported Employment: A Comprehensive Training Conference on Sales and Marketing" will be held at Radisson Hotel South, Bloomington, Minnesota. This workshop is sponsored by Kaposia Works, Inc. and the Brainerd/Staples Regional Technical College. Contact: Customized Training Services, Brainerd/Staples Regional Technical College, Airport Road, Staples, MN 56479. 218/894-3726.

## Lending Library

The following publications are available for a three-week loan. The only cost to the borrower is the return postage.

**The Americans with Disabilities Act: From Policy to Practice**, Jane West (Ed.), Milbank Memorial Fund, 1991. This book presents a synthesis of what we know as a result of research and analysis about establishing and maintaining an accessible and inclusive world for people with disabilities.

**Expanding Options for Older Adults with Developmental "Disabilities: A Practical Guide to Achieving Community Access**, M. Stroud & E. Sutton (Eds.), Paul H. Brookes Publishing Company, (1988). Useful as a training resource for improving services to older adults with developmental disabilities.

**Activities Handbook and Instructor's Guide: For Expanding Options for Older Adults with Developmental Disabilities**, M. Stroud & E. Sutton (Eds.), Paul H. Brookes Publishing Company, (1988). Provides complete instructional plans for self-testing and staff training, with emphasis on community participation.

**Breaking Ground: Ten Families Building Opportunities through Integration**, C.B. Schaffner and B.E. Buswell, PEAK Parent Center, Inc., Colorado Springs, Colorado, 1989. See description on page 3.

**Living Skills: A Guide to Independence for Individuals with Deaf-Blindness**, FIND, Inc. (1991). See description on page 3.

## Copies of Federal Laws Available

The 101st U.S. Congress passed 650 new laws, including a number which relate to special education. The laws listed below can be purchased in individual pamphlet form, known as "slip law," from the Government Printing Office. Note that amendments to existing law, such as the Individuals with Disabilities Education Act (IDEA) of 1990, is the text of the amendments only.

P.L. 101-336, Americans with Disabilities Act of 1990 \$1.50

P.L. 101-392, Carl D. Perkins Vocational and Applied Technology Education Act Amendment of 1990 \$2.50

P.L. 101-431, Television Decoder Circuitry Act of 1990 \$1.00

P.L. 101-476, Education of the Handicapped Act Amendments of 1990 (IDEA) \$1.50

P.L. 101-496, Developmental Disabilities Assistance and Bill of Rights Act \$1.00

P.L. 101-501, Augustus F. Hawkins Human Services Reauthorization Act of 1990 \$1.75

P.L. 101-508, Omnibus Budget Reconciliation Act of 1990 \$18.00

P.L. 101-517, Department of Labor, Health and Human Services and Education and Related Agencies Appropriations Act, 1991 \$1.25

P.L. 101-600, School Dropout Prevention and Basic Skills Improvement Act of 1990 \$1.00

P.L. 101-639, Mental Health Amendments of 1990 \$1.00

To order any of these laws, send check or money order (made payable to Superintendent of Documents) to: Superintendent of Documents, U.S. Government Printing Office, Washington DC 20402, For credit card purchases, call 202/275-3030.

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TIME DATED MATERIAL



# Futurity

Governor's Planning Council on Developmental Disabilities



March 1992

## 'Written Language Potential Is Present In Everyone,'

According to Emergent Literacy Research

Recent research in emergent literacy has led to a conceptualization of literacy learning as a continuous process that begins at birth. "Such a view has **critical** implications for children with developmental disabilities because it implies that the potential for written language learning is present in everyone." This is a major conclusion stated in a recent article:

D.A. **Koppenhaver, P.P. Coleman, S.L. Kalman, & D.E. Yoder.**

(September 1991). The Implications of Emergent Literacy Research for Children with Developmental Disabilities. *American Journal of Speech-Language Pathology*, **1**, (1), 38-44.

The authors are from the **Carolina Literacy Center**, Department of Medical Allied Health Professions, University of North Carolina at Chapel Hill. The following statements are excerpts from this article.

An abundance of literature has resulted from decades of **concerns** about "why Johnny can't read." However, there is virtually nothing on the topic of the reading and writing problems of children with developmental disabilities. In part, this scarcity **stems** from the idea that unless children are "ready" to read, it is a waste of time **to** teach them.

Emergent literacy research is different from the reading readiness predecessor in two **important** respects. First, it takes a broader view in considering, both reading and writing. Second, it attempts to understand literacy development from the child's perspective.

Four important conclusions can be drawn from research in emergent literacy (**Teale & Sulzby, 1986**):

1. The process of learning to read and write begins at birth. Every child, **nondisabled** or disabled, is equipped with varying de-of **visual**, auditory, **and** cognitive abilities that facilitate language and literacy development.
2. Reading, writing, speaking, and listening abilities develop concurrently and **interrelatedly**, rather than sequentially.
3. The functions of literacy are as integral to literacy learning as the forms. Literacy development is best fostered when reading and writing are functional, **purposeful, and goal-directed**.
4. **Children** learn written language through active engagement with their world. Emergent literacy learning is **constructive**, active, and interactive. Children learn to eventually read and write by first observing and interacting with other literate individuals. They learn what to attend to, how to use various materials, and what thinking processes to employ. Parents model literate behavior and attitudes, provide materials and experiences, and shape child behavior indirectly through their expectations of child participation and competence.

**Emergent literacy research suggests that all children, including those with developmental disabilities, learn written language as a by-product of functional, everyday activities involving printed and oral language.** It is now possible to" begin

Continued on page 2.

## Request for Proposals: Community Integration of Persons with Deaf- Blindness

The Deaf Services Division of the Minnesota Department of Human **Services** has issued a Request for Proposals (**RFP**) entitled: "To Increase Independence, Productivity, and the Integration of Persons with Deaf-Blindness into the Community." Two categories of funding will be considered: 1) community integration and **support**, and 2) independent living skills development. Copies of the **RFP** and more information are available from Amy McQuaid, Program Planner, Deaf **Services** Division, Department of Human Services, 444 Lafayette Road, St. Paul, MN 55155-3814. 612/296-8978 (voice), or 612/297-1506 (**TDD**).

## Toll-Free ADA Information Line

The U.S. Department of Justice has awarded a grant to the Disability Rights Education and Defense Fund (**DREDF**) for the establishment of a toll-free telephone **service** to provide **technical** assistance to businesses, state, and local government entities, persons with disabilities and their advocates on the Americans with Disabilities Act. Call between **9:00 a.m. and 4:30 p.m., Pacific time**:

**1-800 -466-4ADA (Voice/TDD)**

## Inside This Issue...

*Lucy Gwin's Personal Story,  
"The Price of Emotions"*

*Studies on Prenatal  
Drug Exposure*

## Prenatal Drug Exposure Study

The Institute on community Integration at the university of Minnesota will be conducting three new studies on the effects of prenatal exposure to drugs and alcohol on children's development. The projects have received first year funding of nearly \$1 million in grants from the U.S. Department of Education, with the total federal support over the next five years projected at nearly \$5 million. The three projects are:

1. **Prenatal Cocaine Exposure and Social Development of Young Children**, a five-year research project to increase knowledge of social development of young children exposed prenatally to cocaine
2. **Prenatal Cocaine Exposure and Mother-Infant Interactions** is an 18 month project that will study early interactions between a group of prenatally cocaine-exposed infants and their mothers in comparison to a group of non-exposed infants and their mothers.
3. **Early Childhood Research Institute on Substance Abuse** is a five-year project to study and develop interventions that address the Unique needs of children affected by prenatal drug and alcohol exposure as well as strategies to improve coordination and continuity of services.  
**Contact:** Mary McEvoy or Scott McConnell, Institute on Community Integration, University of Minnesota, 109 Pattee Hall, 150 Pillsbury Drive, SE, Minneapolis, Minnesota 55455. 612/624-6347.

## Volunteer

### Companions Wanted

FIND, Inc. is seeking volunteers in the Metropolitan Area to serve as companions to persons with hearing and vision loss. Companions provide mail reading, recreation, assistance with shopping, and other community activities. Volunteers receive training in various communication styles. **Contact:** Tom Whitney, Volunteer Coordinator, FIND, Inc., 119 4th Street, North, Minneapolis, MN 55401. 612/333-6901 (voice and TDD).

Continued from page 1

## language Potential

addressing the literacy needs of children with developmental disabilities. Some suggestions for parents and teachers are outlined below.

### Parents

Parents and other family members should attempt to integrate print and opportunities to write or draw in everyday routines.

1. **Open, read, and respond** to mail as the child observes, and help the child hold a pencil and answer some of the letters.
2. Use recipes with the child to bake a cake or cookies.
3. Make out shopping lists with the child and then point out names of items on signs and labels in the store.
4. Read labels of cereal boxes, juice bottles, or canned foods to a child while preparing meals or feeding the child
5. Read and show labels on diaper boxes, powder, and clothing to the child during changing and dressing
7. Watch television like "Sesame Street" with the child and reinforce any written language activities.
8. Make sure that the child has opportunities to observe functional and recreational uses of print such as looking up programs in TV Guide or reading the newspaper
9. Read storybooks to children, relate story events and characters in the stories to the child's own experiences.

### Practitioners

Preschool teachers should incorporate literacy experiences and materials into the children's class routines rather than creating a special literacy learning time. ,

1. Use thematic experiences such as storybook reading, with related art, drama, @cooking activities to help the child understand and integrate concepts.
2. Provide opportunities for children to interact so that they may have models for asking questions, providing answers, commenting, and story retelling.
3. Create and use interactive "storyboards" with or without voice output so that children with severe speech impairments will have away to interact with peers and the teacher during storybook activities.
4. Repeat stories so that the child can internalize concepts and grammar presented in the story.
5. Read a variety of types of children's literature to expose children to different types of language and experiences.
6. Provide independent access to and use of storybooks, writing, and drawing instruments, and other print-related materials. Encourage children to talk about what they have written and drawn.
7. Place print (e.g., labels, ABCs) in the environment within the child's line of vision.

Children learn to read by reading and to write by writing. The potential to achieve some level of literacy is present in every child, and the development of that potential depends almost entirely on the opportunities provided within the child's supportive environment.

## The Price of Emotions by LUCY Gwin

Lucy Gwin survived a severe brain injury in 1989. She had made *her living as a writer for 23 years. These days she writes, rabble-rouses, and is the editor of This Brain Has A MOUTH!*



My family is no more. My business is **no** more. Many of my friends have avoided me. These are the prices of emotion. Emotion **is** banned for survivors, whether it be sadness, or fear, or anger, or laughter, or love. People have learned a lot of **scary** things about us. **Who does the teaching?**

**Recently I got hold** of some reports about a survivor of head injury. The people who wrote the reports **were professionals--** the survivor was me. Reading the reports, and remembering what incidents they refer to, the price of emotion becomes clear.

I experienced my **first** weeks back alive as a glorious reawakening to the ordinary miracles of everyday life. Glorious, all. I was alive! Now life had become suddenly more real, more **saturated** with color and sound **and** movement.

Meanwhile, the experts took notes, wrote **reports**. Everything I said and did proved to them how **sick** in the head I was. A fellow survive? literally hugged me back to life. The official reports describe our lifegiving hugs as "sexual acting out."

Another survivor said something that made me laugh for the first time since the coma. Laughing felt **so** good that I didn't want it to stop, ever. **I** let it ripple through me. The official reports described my joyous laughter as, "emotional lability."

One **day** while I stood in line for reeds, I realized that my life had changed forever, that I might never have my freedom or my own independent life again. I shed two quiet tears. "The professionals hustled me off to isolation. The reports of that incident **described** me as "profoundly depressed and in need of psychotropic drugs."

I refused to wear a certain kind of uncomfortable underwear. I said no thanks. They insisted. I told them that I'd cut it into tiny **pieces**. The reports mad, "threats of violent behavior," called me "abusive."

Everyday I asked for a toothbrush, shampoo, 'soap, shaving equipment. Most days, I didn't get them--brushed **my teeth with** my fingers, washed my hair with water. The reports called me "unkempt."

**I asked for** a pert and a notebook. They asked why I would want such things; after all, I'd never be a writer again. I was stunned. "But writing is my life," I choked. The reports said I was "on an emotional roller coaster."

I told them that I wanted to go home, that I wanted to learn my rights, that **I wanted** to see a medical doctor and **learn** my prognosis. They wrote up my requests as "**presevation,**" and denied them.

If the person **described** in these reports had **been a relative of mine**, I wouldn't have invited him into my house. Violent? Abusive? Sexual acting out? On an emotional roller coaster? **Hey**, keep him. I've got enough problems.

My friend **Jamie** and I want to spend our time living, not proving to "the others" that, "Hey, they can **think!**" **We're human beings. We don't have to prove anything more than that.**

Source: *The Journal of Head Injury* (1991), Vol. II, No. 3, pp. 48-50.

## Events

**March 20, 1992**

"Americans with Disabilities Act (ADA) Is Good Business" conference will be held at the Sheraton Park Place Hotel in St. Louis Park, sponsored by SuperAmerica, Courage Center, Minnesota Multiple Sclerosis Society, and the Minnesota State Council on Disability. Intended audience: Employers. **Contact:** Cindy Tarshish, MS Society 612/870-1500, or Ann Roscoe, Courage Center 612/520-0210.

**May 26-30, 1992**

The American Association on Mental Retardation will hold its 116th Annual Meeting, "New Realities, New Challenges, New Orleans," at the New Orleans Hilton Riverside and Towers. **Contact:** AAMR, P.O. Box 1202, Washington, DC 20013-1202.

### Mark Your Calendars

**October 1992**

The Minnesota Disability Awareness Coalition has chosen October to be Disability Awareness Month for 1992. There will be a rally at the State Capitol on Saturday, October 3rd, from 1:00 p.m. to 3:00 p.m., in the Capitol Rotunda. **Contact:** Nancy Booker, 612/887-9132 (voice), 612/887-9144 (voice/TDD).

### Why People Resist Change: What Leaders Should Know by Sandra K Fabian

1. The purpose for the change has not been made clear.
2. People have not been involved in the planning.
3. The appeal is based on personal reasons.
4. The norm and habit patterns of the community are ignored.
5. There is poor communication regarding change. When **people don't know**, they vote no.
6. There is fear of failure. Most people would rather **plead** lack of interest rather than ignorance or fear.
7. The cost is too high or the reward for making the change is **seen** as inadequate.
8. The present situation seems satisfactory.

Source: *New Directions* (Winter 1992), Concordia Leadership Center, Concordia College, Moorhead, MN, p. 2.

## Lending Library

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

***With a Little Help from My Friends*** (VHS--One hour), produced by M. Forest and G. Flynn, Toronto, Ontario, Canada. Depicts use of Making Action Plans (MAPS) in an integrated classroom.

***LRE (Least Restrictive Environment)***: A Policy of Inclusion, Minnesota Department of Education (1992). Highlights integrated classrooms in several Minnesota communities. Narrated by news anchor Don Shelby, WCCO-TV.

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

***Special Students, Ordinary Classrooms***, TV 6 News, Kitchener and Waterloo, Ontario, Canada. Initial doubts about integrated classrooms change to enthusiasm by school administrators, teachers, parents, and children.

***Conservatorship and Guardianship in Minnesota (1990)***. Describes options, ethics, and responsibilities when making substitute decisions on behalf of persons with developmental disabilities; promotes self-determination.

## Publications/Resources

Answers to *Your Questions About Epilepsy*, Epilepsy Education, University of Minnesota, 1992. This newly revised brochure addresses issue that young people deal with every day. They wonder about drinking, driving, use of medications, marriage, family planning, employment and more. Many solutions depend upon personal choices. Price: \$0.75 per copy, plus \$1.00 postage and handling. **Contact:** Epilepsy Education, University of Minnesota, 5775 Wayzata Boulevard, Suite 255, Minneapolis, MN 55416. 612/6274477.

***Inclusive Education for Learners with Severe Disabilities: Print and Media Resources (1991)***, Institute on Community Integration, University of Minnesota. This fourth updated version includes resources about successful inclusive education models and strategies. Topics include: rationale, systems change and restructuring, collaborative teamwork, curriculum and instruction, social interactions and friendships, family perspectives and issues, and personnel training. **Contact:** Minnesota Inclusive Education Technical Assistance Program, Institute on Community Integration, University of Minnesota, 111 Pattee Hall, 150 Pillsbury Drive, SE, Minneapolis, MN 55455, 612/ 624-1349.

1992 ***Catalog: Publications in the Human Services***, Paul H. Brookes Publications Company. The Brookes Publishing Company has been recognized for its outstanding publications about disabilities. Some categories of literature include: family resources and issues, community integration, employment, education, communication, policy and service issues, and professional development. **Contact:** Brookes Publishing Co., P.O. Box 10624, Baltimore, MD 21285-9945. 1-800-638-3775.

***Catalogue 1991-1992: The Roehrer Institute***. The Roehrer Institute is Canada's National Institute for the Study of Public Policy Affecting Persons with an Intellectual Impairment. This information service includes a library, a book and film distribution service, and a computer-accessible information system. The Institute also publishes the quarterly magazine "entourage," in addition to providing a variety of education programs and workshops. **Contact:** The Roehrer Institute, Kinsmen Building, York University, 4700 Keele Street, North York, Ont. M3J 1P3. 416/661-9611.

## Futurity

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April 1992

## The Challenge of Advocacy for the '90s: Making Choice Real by Clarence J. Sundram

We have all been witnessing the accumulated effects of advocacy efforts of the past two decades. Today, we are hearing bold new visions articulated, not just by powerless dreamers, but by elected and appointed governmental officials and by **key** leaders in the community of professionals that serve people with disabilities. **These** new visions and changes have important implications for each of us, in a very personal way.

Today the buzz word in our field is "choices." We **are all** talking about providing choices so individuals with disabilities can express their personal preferences. But I invite you to think about how consumer participation has often worked in practice. First, very often we found surrogates to speak for people with disabilities. Second, we often ignored whatever the consumer wanted when it was inconvenient or challenged us to do things in unfamiliar ways.

One of the most significant challenges that we are going to face as advocates is making choice real for people with disabilities. I think we have tended **to** jump on the bandwagon supporting the notion of choice without adequately thinking through how profound a change in behavior this is going to require from all of @ whatever our role in the human service system.

A recent **experience** gave me a fleeting glimpse into how the presence of a disability shapes our attitudes towards people, **and** how much we have to overcome. While hiking up a mountain with a group of **casual** acquaintances, I twisted my knee. I could no longer maintain the pace with the leaders and soon fell back, passed **by the** young and the old as I limped along. When I met my party at the top of the mountain and the effect of my injury became evident, everyone had an opinion about what was best for me. I didn't recall bumping my head or losing **my** ability to think, but somehow my opinion seemed to be blithely dismissed as if it wasn't even worth discussing. My own image of myself began to change in the process.

If all this is happening to me, I thought, **what** must people with lifelong disabilities be going through? How **must** it feel to be disregarded, dismissed, or **patronized**?

When we commit ourselves to listening **to** people with disabilities, the task isn't as simple as asking a question and recording and acting on an answer. I suspect we all know that **intellectually**. But how is it going to change what we do?

Leonard **Kriegel** said in his book, *Falling into Life: Essays*, "People struggle not only to define themselves but to avoid being defined by others." Are we willing to **undertake** the responsibility of helping people with disabilities find their authentic voice, perhaps a voice that has long been silenced, to impose their real selves on the world?. How do we do it? Do we listen only to those who can speak in our own language? Will we have the patience to develop the "types of relationships in which real communication about important things is possible? Or will we be pressured to do what is convenient, and to exalt form over substance in listening to their voices? My **purpose in raising these questions** is to urge revolutionary **thinking about** how

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"How **lovely** to think that no one need wait a moment: We can start now, start slowly changing the world! How lovely that everyone, great and small, can make a contribution."

ANNE FRANK  
1929-1945

## Respite Care Hours Expanded Under Waiver Programs

**As** a result of a **recent** change in federal policy, Minnesota's request for an amendment to expand the amount of respite care services available to all eligible waiver respite care recipients was approved in February 1992. This announcement was made by the Department of Human Services in Informational Bulletin #92-61B, March 10, 1992.

Prior to the amendments, there was a federally imposed limit of 30 days or 720 hours on the amount of respite **care** that could be provided to a person receiving services through Title XIX Home and Community-Based Services to Persons with **Mental** Retardation or Related Conditions, including Enhanced Funds, and Attendant **Care Services** *waked* programs.

*The* Department's approved amendment **now allows up to 90 days or** 2,160 hours of respite care to be provided to an individual  
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Inside This Issue...

*Supported Employment Opportunity  
for Social Integration*

*Volunteers Needed for National  
Study on Families*

## Certificate Program Offered at University

The Institute on Community Integration at the University of Minnesota is sponsoring specialized training through the Interdisciplinary Studies in Developmental Disabilities Certificate Program. This best practices training is intended for human services professionals, community members, educators, and university students from a variety of majors. Content includes inter-disciplinary teamwork, consumer/family empowerment, individualized services and supports, and community integration.

For a brochure or more information, contact: Kay Almer, 612/625-333%.

## Volunteers Needed

The Child Guidance Center in conjunction with the University of Nebraska-Lincoln is conducting a nationwide study of the positive and negative effects of a developmental disability upon the individual and the extended family. Persons with developmental disabilities and their family members are being requested to participate in the study by completing a questionnaire. Questionnaires are available for all ages and family roles: child or adult with a disability, mother, father, sibling, grandparent, etc. If you are willing to volunteer for the study, please send your name, address, and tell about which type of questionnaire you need. Call or write to: Susie Dahl, Child Guidance Center, 215 Centennial Mall South, Room 312, Lincoln, NE 68508. 402/475-7666.

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## ADVOCACY

We grapple with implementing a bold new vision of meeting the needs and preferences of people with disabilities.

We must think about the task of remaking ourselves into better and more effective listeners. Changing the world for people with disabilities is a personal task for each one of us.

[Source: Clarence J. Sundram is the Chairman of the Commission on Quality of Care, Albany, New York and this article is abridged from his keynote address at the 1991 New York State American Association on Mental Retardation Conference, Tarrytown, New York, October 2-4, 1991.]

## Supported Employment: Opportunity for Social Integration

Social integration of employees with disabilities in the workplace is a significant outcome of supported employment. The following suggestions are intended as a place to start when encouraging variety and choice in interpersonal relationships at work:

- Introduce the employee with a disability into the natural groupings at work.
  - Provide opportunities for co-workers to get to know the employee with a disability.
  - Brainstorm activities that would enable the employee to contribute to the natural groupings at work.
  - Decide whether or not training inhibits choice and adjust training strategies accordingly.
  - Allow for personal choice in social settings at work by minimizing support involvement.
  - Suggest that co-workers encourage variety and choice as they typically do for other employees.
  - Explore the interests and hobbies of the employee to discover possible overlap with co-workers.
  - Consider ways to help the employee to contribute to the group.
  - Redesign existing jobs to require more work related interactions.
  - If nonspeaking employees with disabilities are not interacting with and are not understood by co-workers, consider alternative communication systems.
  - When alternative communication systems are used, teach co-workers how to use them and provide feedback until co-workers are comfortable with them.
- [Source: *The Integration Guide*, D. Sandow, D. Mank, L. Rhodes, and W. Taliaferro, The Specialized Training Program, University of Oregon, 1761 Alder Street, Eugene, OR 97403.]

## Publications

*Kids Can't Wait: Action for Minnesota's Children; Report to the Governor and People of Minnesota*, Action for Children Commission, Minnesota Planning, February 1992. This publication documents issues and trends, and makes recommendations for strengthening Minnesota families. The report marks the beginning of a process for everyone to become involved to assure a better future for all children. Contact: Action for Children, Minnesota Planning, 300 Centennial Building, 658 Cedar Street, St. Paul, MN 55155. 612/241-156.

*"Parents . . . If you see any of these warning signs . . . Don't delay!"* are brochures and posters developed by Pathways Awareness Foundation. The brochure illustrates both normal development and developmental delays in very young children and carries the endorsement of the Illinois Chapter of the American Academy of Pediatrics. Brochure price: \$17.00/100 copies in English and Spanish. Poster Price: \$5.00. Payable to Pathways Awareness Foundation, 123 North Wacker Drive, Chicago, IL 60606. 1-800/955-2445.

*Growing Up Capable: Living and Learning with Simple-To-Use Technology*, AbleNet, Inc., Minneapolis, 1991. This packet includes a 9-minute VHS videotape and a viewer's guide. It describes creative and practical uses of simple technology which allow children with disabilities to participate, achieve independence, and have fun. A number of AbleNet products are featured as a representative sample of available devices. Price: \$38.00. Contact: AbleNet, Inc., 1081 Tenth Avenue, SE, Minneapolis, MN 55414. 612/379-0956, or 1/800/322-0956, toll-free.

# Events

**April 27, 1992 (2:00 p.m. to 8:00 p.m.)**

Families of children with disabilities are invited to a **free** Pediatric Rehabilitation Equipment Fair at the Gillette Technology Center, 550 County Road D, #12, New Brighton. Exhibits and brief presentations feature current innovations in toys, home modifications, **assistive** technology, and more. Contact: Gillette Children's Hospital at (612)229-3900.

**April 28, 1992 (Seminar I) and April 29, 1992 (Seminar II)**

Featuring Gary W. La **Vigna**, two separate seminars will be presented at the **Holiday Inn St. Paul/Roseville**, 2540 North **Cleveland**, St. Paul, MN. Seminar I: "Basic Principles of Positive Programming and Nonaversive Behavior Management." Seminar II: "Behavioral Assessment and Reactive Strategies." Contact: Institute for Applied Behavior **Analysis**, 6169 St. Andrews Road, Suite 1223, Columbia, SC 29212-3146. **803/731-8597**.

**April 29-May 1, 1992"**

"Minnesota Women's Institute for Chemical **Health: Strengths, Skills, and Strategies for the 90s**" will be held at the **Earle** Brown Continuing Education Center, University of Minnesota. The Institute is sponsored by the Chemical Dependency Program Division, Minnesota **Department** of Human **Services**, and the Professional Development and Conference Services, continuing Education and Extension, University of Minnesota. Contact: Carol Siegel, Professional Development and Conference Services, 235 **Nolte** Center, 315 Pillsbury Drive, SE, University of **Minnesota**, Minneapolis, MN 55455-013. 612/625-5059.

**April 30, through May 2, 1992**

"Changing the Odds: Moving **Children** from Risk towards Resiliency" is a midwest **regional** conference that will explore protective factors that support resiliency in youth at risk. **Sponsor:** Consortium of Minneapolis and St. Paul Organizations and **Agencies** Serving At-Risk Youth. Location: Bloomington Marriott Hotel, Bloomington, MN. Contact: Chris **Carlstrom**, Continuing Education and Extension, University of Minnesota, 214 **Nolte** Center, 315 **Pillsbury** Drive, SE, Minneapolis, MN 55455-0139. 612/625-1520.

**May 8, 1992" (10:00 a.m. to 3:30 p.m.)**

"**Reasonable Accommodations at the Worksites**" is an **ITV** seminar for employers to learn more about the requirements of the Americans with Disabilities Act, which **will** be available at the following **Technical Colleges:** Brainerd/Staples, **Alexandria**, St. Cloud, St. Paul, and Pine **City**. Contact: Naomi **Beachy**, Staples **Technical College**, 218/894-3726.

**May 26-30, 1992**

The American Association on **Mental** Retardation **will** hold its **116th Annual Meeting**, "New Realities, New Challenges, New Orleans," at the New Orleans Hilton Riverade and Towers **Contact:** AAMR, **P.O.** Box 1202, Washington, DC 20013-1202.

**June 19, 1992**

**1992 Minnesota Round Table--"A Blueprint for the 21st Century: The Education of Young Children"** will be held at the **Earle** Brown Heritage Center, Brooklyn Center, **sponsored** by the Center for Early Education and Development (**CEED**), University of Minnesota **Contact:** **CEED**, **University** of Minnesota, 226 Child Development Building, 51 East River Road, Minneapolis, MN 55455-0345.

## Call for Presentations

National, state and local presenters are being sought to focus on practical applications of **assistive** technology for persons with disabilities at a **regional** conference, entitled "Breaking Boundaries through **Assistive Technology**." The conference **is a collaborative** effort between Iowa, **Nebraska**, South **Dakota**, and **Minnesota**, and **will** be held at the Sioux City Convention Center, Sioux City, Iowa. **Contact:** Breaking Boundaries Conference, c/o Western **Hills Area** Education Agency, 1520 **Morningside** Ave, Sioux City, IA 51106. 712/274-6080.

## Nominations Requested

The North **Central Regional** Information Exchange (**NCRIE**) shares information on programs and **practices** which are identified as "exemplary" in their **ability** to serve individuals with disabilities within Region V (i.e., **Illinois**, **Indiana**, Michigan, Minnesota, Wisconsin, and Ohio).

Nominations for exemplary programs **are** being **accepted regarding:** 1) **interagency** collaboration and coordination in programs on transition from school to work; 2) Emergent issues in supported employment, such as the use of **natural** supports and coworker **involvement**; and 3) **parent-professional** collaboration in the integration of **individuals** with disabilities in education, community living, and employment. **Contact:** **North Central** Regional Information Exchange, Institute on Community Integration, University of Minnesota, 6 Pattee Hall, 150 **Pillsbury** Drive, SE, Minneapolis, MN 55455. **612/624-4848**.

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### RESPITE CARE

within a **state** fiscal year (July 1 through June 30) as authorized by the county board in the individual service plan. In addition, there is no **longer** a 30 day limit on the amount of allowable **out-of-home** respite care **services** that maybe provided per state **fiscal** year.

This amendment is approved retroactively to July 1, 1991. **Therefore**, county boards may authorize additional respite care services during the **current fiscal** year. **Contact:** Alex Henry **Bartolic** (612/296-0939) or **Barb** Roberts (612/296-1 146), Division for Persons **with** Developmental Disabilities.

## Lending Library

The following publications are available for a three-week loan. The only cost to the borrower is the return postage.

*Enabling and Empowering Families: Principles and Guidelines for Practice*, C. J. Dunst, C. M. Trivette, and A. G. Deal, Brookline Books, 1988. helping families to cope more effectively on their own. Serves as a guide for the implementation of early intervention programs for youngsters with disabilities and their families.

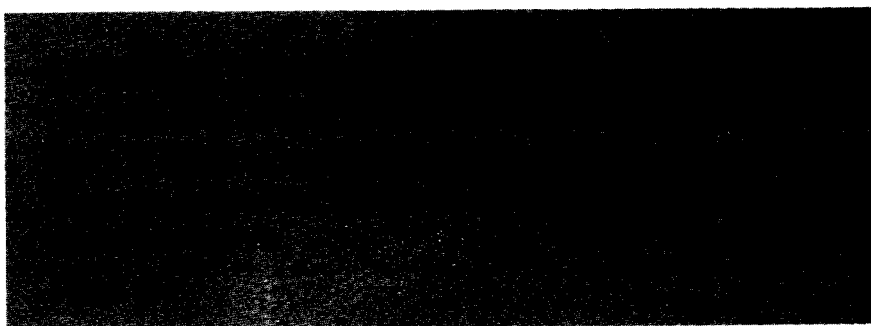
*Developing Individualized Family Support Plans: A Training Manual*, T. Bennett, B. V. Lingerfelt, and D. E. Nelson, Brookline Books, 1990. Based on successful experiences in Morgantown, North Carolina, this guide builds competencies of families through partnerships between parents and professionals. Case studies provide concrete examples for writing Individual Family support Plans (IFSPs).

*Organizing for Social Change: A Manual for Activists in the 1990s*, K. Bobo, J. Kendall, and S. Max, Seven Leeks Press, 1991. This guide was developed out of curricula and experiences of the Midwest Academy, founded in Chicago in 1973, and provides tools for action toward social change in a participatory democracy.

## Client Assistance Project Provides Linkage to Rehabilitation Services

The Client Assistance Project (CAP) of the Minnesota Disability Law Center, is a statewide advocacy project which helps people get the vocational rehabilitation services they are entitled to by law. One of the priorities of the project is to assist people in securing supported employment services from the Division of Rehabilitation Services and State Services for the Blind. CAP can provide information, review cases, negotiate with counselors, and represent people in appeals.

A recent CAP publication can be helpful to those who want to know more about supported employment--How to Get Supported Employment Services from the State Vocational Rehabilitation Agency. This is a fact sheet which tells about supported employment and how to apply for these services. "With supported employment as a service option, the severity of the disability should not be a reason to be found ineligible for vocational rehabilitation services," the authors state. Contact: Client Assistance Project, 430 First Avenue North, Suite 300, Minneapolis, MN 55401-1780. 1-800-292-4150 (toll-free), or 612/3321441 (Twin Cities), or 612/332-4668 (TDD).



## Futurity

DEPARTMENT OF ADMINISTRATION

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# Futurity

Governor's Planning Council on Developmental Disabilities



May, 1992

## Youth with Disabilities Fare Poorly after School According to National Follow-up Study

In a recent nationally representative study of 8,000 special education students, only 46.4 percent of those who had left school after one or two years were competitively employed in full or part time jobs. The results of the first two years of a National Longitudinal Transition Survey is reported in *Youth with Disabilities: How Are They Doing?*, conducted by SRI International, Menlo Park, California.

By type of disability, those finding employment after high school were as follows:

### TYPE OF DISABILITY BY PERCENT EMPLOYED

|                         |       |                     |       |
|-------------------------|-------|---------------------|-------|
| All Conditions          | 46.4% | Learning Disability | 57.2% |
| Emotionally Disturbance | 40.0% | Speech Impairment   | 50.0% |
| Mental Retardation      | 31.4% | Visual Impairment   | 24.3% |
| Hearing Impairment      | 45.5% | Deaf                | 38.3% |
| Orthopedic Impairment   | 139°A | Multiple Handicaps  | 5.7%  |
| Deaf/Blind              | 9.5%  |                     |       |

Both the type of disability and its severity has an important influence on success, according to SRI's mid-point data, part of a five-year look at the transition from special education into work, training, and independent living.

On a positive note, nearly 70 percent of the special education students, particularly deaf students and those with learning disabilities, rose above counterparts in special education and were as productive in the first and second year after high school as nondisabled peers in the general population.

More than 90 percent of special education secondary students in the study attended regular schools, and almost 80 percent took at least some of their courses in regular classrooms. The average amount of time spent in regular education in this study was 56 percent, with some students spending a high of 77 percent, and students with more severe disabilities dipping to 19 percent. Over@ however, only 17 percent of the special education students took all of their courses in regular education

Socioeconomic levels were significantly related to classroom placement. While the amount of time spent in regular education classes hinged largely on disability, wealthier students and those who were younger, irrespective of disability, spent the most time in regular education.

Those students in the study who attended school in separate buildings, tended to be those who were deaf, visually impaired, or had

Continued on page two

## Teleconferencing Links Minnesota to the World

Minnesota is equipped with an extensive satellite telecommunications network linking the entire state through the technical college system. The Minnesota Satellite and Technology (MnSAT) network consists of 34 permanent KU band receiving (downlink) sites located at every technical college; a permanent sending (uplink) facility at the St. Paul Technical College; and a television production studio on the fifth floor of the Minnesota World Trade Center Building in downtown St. Paul. Broadcasts are usually from one location to many locations throughout the state, the country, and the world. Many colleges, universities, and hotels have facilities designed for receiving video teleconferences.

Live, interactive video teleconferencing can be an effective tool to save time, cut travel costs, convey timely information and/or assist decision making through enhanced communications. For more information, contact: MnSAT, 500 Minnesota World Trade Center, 30 East Seventh Street, St. Paul, MN 55101. 612/296-2383.

### Inside This Issue...

*Interview with Arthur Weld, enthusiast of facilitated communication*

*Amnesty International to Review Aversive Procedures*

*Readers evaluate Futurity*

*Not until we can refuse to take without giving, can we create a society in which the chief activity is the common welfare.*

Helen Keller (1880-1968)

## Home's Only as Far Away as the Palm of Your Hand

Phone Home, an **automatic** dialing device, enables lost children and elderly or people with **disabilities** to call their homes even **if they** do not know **their** number, **or** how to dial. The device will fit into a child's hand and can be clipped to clothing or a key chain. It is held to the mouthpiece of a telephone and its "home" button pressed; that activates the phone company's tone-dialing system and gets an **operator**. Phone Home, which uses **two** alkaline cell batteries, is the invention of Stephen Bethel, **president** of Nimrod International Sales, Inc. in Clarksburg, New Jersey. The device is available in discount and variety stores for \$19.95 and **can** be ordered by calling 1(800)+17-51%.

Source: *New York Times*, February 22, 1992, p. 16

Continued from page one

## Y o u t h

multiple disabilities. Students with severe impairments or serious emotional disturbance generally fared the **worst**, both in school and out. For example, arrest records of students with serious emotional disturbance were at the 19.6 percent level while in high school, but, soared to 43.8 percent once they were out of school for more than a year.

Copies of ***Youth with Disabilities: How are They Doing?*** is available for **\$40.00, prepaid to: SRI International, B.** S128, 333 Ravenswood Ave., Menlo Park CA 94025.

## Readers Respond to Futurity Survey... Thank you!

An evaluation card was **attached** to the February issue of *Futurity*, and better than one-third of the readers responded. That is, 501 out of 3,000 people from throughout the United States, Canada, and other countries **helped** us to evaluate this over-one-year-old newsletter.

Asked **to** score *Futurity* on a scale from one to ten, with ten as the highest, the overall score was 7.70. Most readers have found value **in** the information provided, with frequent comments saying that *Futurity* has **helped** them to keep informed on **current/cutting-edge** issues, events, and literature.

There is a wide audience among the readership: school personnel, early childhood interventionists, others who work with people who are aging, higher education teachers/trainers, human service **personnel** (e.g., case managers), rehabilitation and employment staff, health care professionals, administrators and **policymakers**, residential service providers, day program personnel, parents and family members, and people with disabilities.

**While** some wanted more **in-depth** coverage, most seemed to like the current style-concise summaries with directions as to where more information can be obtained if needed. Suggestions for improvement are always welcome. The respondents listed: Include more about the activities of the Governor's **Planning** Council on Developmental Disabilities and grant recipients. Also, more information is desired regarding: early childhood; the "**how-tos**" of integration, making choices, and **making** friends; employment opportunities; new legislation and governmental publications; and independent living options and trends.

**Several** people mentioned disappointment that ***D.D. Information Exchange*** (published jointly by the Metropolitan Council and the Governor's Planning Council on Developmental Disabilities, 1973-1990) no **longer** was being published. *Futurity* was created to fill the 'void when the Metro Council decided to discontinue their involvement.

We will try to address your interests in the future. Thank you for responding, and thanks for your encouraging comments.

**The Editor**

## New Hampshire Home Ownership Project

**The** University of New Hampshire's Institute on Disability is in the early stages of a three-year project to promote home-ownership for people with developmental disabilities. Financed through a grant from the federal Administration on Developmental Disabilities, this project will design home ownership strategies for 25 people with developmental disabilities from across the state. The project is a collaborative effort involving the Institute, the New Hampshire Developmental Disabilities Planning Council, the State's Disability Rights Center, the Division of Mental Health and Developmental Services, and the New Hampshire Housing **and** Finance Authority. For more information, contact: Jay **Klein**, Institute on Disability, University of New Hampshire. 603/862-4320

# Finding the Words: An Interview with Arthur Weld

by Bill Lynch



For the first 29 years of his life, Arthur Weld had no effective means of expressing his thoughts. At age 4 he was labeled severely mentally retarded. In special education he learned a few words of sign language. Upon leaving school, he began his employment at Olympus Electronics in Seattle, where he still works as an electronics assembler. Last September, Arthur was introduced to facilitated communication, a relatively new technique designed for people with limited speech-whose intelligence is hidden by a communication deficit.

Facilitated communication was developed in Australia, and is a simple (though controversial) technique that can produce dramatic results. All that is required is a computer keyboard, electric typewriter, or alphabet board, and the assistance of someone who supports the hand, wrist, arm, or elbow of the typist.

The following interview was conducted by Bill Lynch, University of Oregon, over the telephone, with Arthur returning his responses via fax machine. Q: Some people doubt that facilitated communication is real. They don't think you are really typing the words. Do you have anything to say to assure them about the validity of this technique? Arthur: Yes. Tell them to learn more about facilitated communication. They will believe it when they learn more. Q: How does facilitated communication work? What does it feel like when you have your hand supported? Arthur: It feels like I can control my hand. The support lets me move my hand where I want it to move. With it I touch the right keys most of the time. Sometimes I can touch the right keys without support but not very often. I want to learn to type alone. Q: How did you learn to read and spell? Arthur: I learned to read in school. When the teacher was teaching, I was listening. When they thought I was retarded, I wasn't. When they thought I couldn't learn, I could. When they thought I wasn't listening, I was. Will they start to believe that others are listening? Tell them to believe it. Q: How has this affected your life? Arthur: It has made my life much

Continued on page four

## Amnesty International to Review Aversive Procedures

The USE of aversive procedures on people with developmental disabilities is still being reviewed. Amnesty @looking at situations where people have been abused in the name of therapy (i.e., subjected to "treatment" which would not have been administered to a person without a disability). Anyone with a statement or information about people willing to make a statement should contact: **Herbert Lovett, Ph.D.**, 76 G Street, Boston, MA 02127-2919. 617/269-8382.

## Events

**May 20, 1992 (9:00 a.m. to 4:30**

**p.m. "Marketing and Consumerism"** is a forum relating to products in assistive technology, sponsored by The STAR Program. The forum will be held at **Minneapolis** Marriott-Bloomington, 2020 East 79th Street, Bloomington, MN. Contact: Susan Rest, 612/296-9718 (voice), or 612/296-9962 (TDD).

**June 3, 1992 "Leadership Roles in Changing Times"** is the 34th Annual Institute on Aging that will be held at the St. Cloud Civic Center, sponsored by the Minnesota Board on Aging. Contact: Diane E. Levitt, Minnesota Board on Aging, 444 Lafayette Road, St. Paul, MN 55155-3843. 612/296-3867, or 1-800-652-9747.

**June 10, 1992 The Minnesota Developmental Achievement Association will present "The Wit To Win,"** a workshop for integrating older persons with developmental disabilities into community programs. Presenters: Matthew Janicki and Phillip Lepore. Place: Sheraton Inn Midway, St. Paul, MN. Contact: MnDA CA, 1821, University Avenue, Suite 277, St. Paul, MN 55104. 612/264-9200

**Mark Your Calendar October 15-17, 1992**

The Arc United States Convention "Coming Home - Reflect the Past Realizing the Future." will be held at the Marriott Hotel in Minneapolis, MN. Contact: The Arc National Headquarters, 1-800-433-5255

## Lending Library

The following resources are available for a three-week loan. The only cost to the borrower is the return postage.

**"Listen Lady, This is My Life": A Book of Stories about Personal Futures Planning in Minnesota, Human Services Research and Development Center, St. Paul, 1992.**

Personal Futures Planning is an individualized, structured possibility-based approach to life planning—a process where people make commitments to certain actions to help bring dreams into realities.

**Curriculum Considerations in Inclusive Classrooms: Facilitating Learning for All Students, S. Stainback and W. Stainback (Eds.), Paul H. Brookes Publishing Company, 1992.** Several authors contribute their perspectives on how to attain quality educational programs for all children in inclusive settings. As described by Marsha Forest and Jack Pierpoint in the Foreword, "Inclusion . . . is about changing our hearts and our values."

**Employees with Disabilities: A Guide for Co-Workers of Individuals with Disabilities, Institute for Human Resource Development, Inc. Glastonbury, Connecticut, 1992.** Workers with disabilities can be excellent colleagues if provided with the necessary assistance or support. Co-workers of people with disabilities are critical partners for ensuring successful employment outcomes for both them and their businesses.

Continued from page three

### Arthur Weld

better. Now I can tell everyone that I am intelligent. People treat me with more respect. I wished for a long time that I could talk to my mom. Now I can. Carol was very patient with me. I am very grateful to her. Q: How did it feel to be labeled mentally retarded? How did you cope with that label? **Arthur:** It felt terrible. I wanted to tell everyone that I was smart. I dealt with it by just trying to realize that they didn't understand. Q: Do you have any new plans for your future now that people are able to understand you better? **Arthur: Yes.** I want to teach others about typing. I want to go to college. I really desperately want to teach others. Q: Do you have any advice for people who are learning to type? **Arthur:** Keep trying. It will get easier for you. It is very hard at the beginning, but it gets better. Q: Any advice for the people who are teaching facilitated communication? **Arthur: Yes, you** must be very patient. The person you are teaching is excited and scared. Type with them every day. They need you to type with them often. Q: Anything else? **Arthur: Yes, I** want you to teach everyone about this. It is very important to us. I want to say that I am worried about the other people. They must learn to type.

**Source:** This article is reproduced with permission from *Arc news* of Oregon (March 1992). Bill Lynch works for the Specialized Training Program at the University of Oregon in Eugene. Pictured with Arthur is Carole Crane, Supported Employment Coordinator, Arthur's facilitator at Olympus Electronics.

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