

## Results of a National Study: Families Do Make a Difference!

During the spring and summer of 1992, the Human Services Research Institute (HSRI) conducted a nationwide study, surveying state administrators on the current status, and expected future status of family support programs. At that time 46 of the 48 states that provide family support services responded, and information about a total of 70 programs was obtained. Summary of the findings are as follows:

- **Description of Family Support Programs:** Of the 70 programs, 21 are cash subsidy or voucher programs, 13 provide funding for respite services, only, 33 provide some combination of support services (e.g. respite, cash subsidy, parent training, independent living,) and 4 programs provide other services not fitting into these categories (e.g. infant development).
- **Legislative Mandates:** The number of family support programs mandated by law has increased dramatically since 1990. Thirty-two programs within 25 states now have some form of legislation, compared with 20 programs in 1990.
- **Budget Cuts:** Respondents indicated that 19 percent of the family support programs would most likely experience some level of budgetary cutbacks in the upcoming year. This represented 13 of the 70 programs nationwide.
- **Anticipated Increase in Families Served:** Two-thirds of the respondents envisioned an increase in the number of families receiving services from their programs. However, over half (57 percent) expected their waiting lists to get longer.
- **Eligibility Criteria and Limits on Benefits:** Most indicated that these would be unchanged (85 percent and 71 percent, respectively).
- **Influence On Decision-Making Process:** Administrators for each family support program were asked to rate the amount of influence that seven different individuals and groups ultimately had in helping to reach the budgetary decisions that were made for the upcoming year. Family members of persons with disabilities and agency staff were perceived by more than half of the respondents as having large amounts of influence.
- **Appropriations:** The amount of money designated for family support services has increased nearly two-fold since the study in 1990.

**Conclusion:** "While current and future investments in families seem threatened, the move to support families is taking hold. These survey findings clearly show that families do and can make a difference! In these coming years, the challenge to families is to recognize their capacity to influence the decision-making process and to use it in shaping public policy."

Copies of *Policy Brief on Family Support: Results of a National Study: Families Do Make a Difference!* (September 1992) by Kerri Melda & John Agosta, may be requested from: Human Services Research Institute, 525 Glen Creek Road, Northwest, (#230), Salem, OR 97304.

## Thanks for Speaking Out, Minnesotans!

Approximately one thousand people shared their experiences and views during the town meetings and call-in day held last summer. Input was requested by a Study Group appointed by George Steiner, Deputy Commissioner, Department of Human Services in January 1992. Their mission was to review the current structure under which services to people with developmental disabilities are provided and to review costs. The final report has now been completed and disseminated, called: *Minnesotans Speak-Out!*, presented by The Governor's Planning Council on Developmental Disabilities (November 1992).

The report summarizes the themes discussed at the town meetings: 1) "We have a lot to be proud of and much remains to be done!"; 2) individualization; 3) staffing; 4) leadership and bureaucracy; 5) inequity of resources--inconsistency in the system; and community programs and support. The report concludes with specific recommendations from the study group regarding: individual and family support; funding and quality assurance; waiver programs; array of services and options; coordination; case management; guardianship; and need for adequate planning data. Copies of the report may be obtained from the Governor's Planning Council on Developmental Disabilities. See return address on page 4.



### Inside This Issue...

- "Never Say Never;" Johnstone Closes in New Jersey
- World Agenda on Disabilities--Part Two
- Exemplary Programs/Practices Sought

## Nominations Requested on Exemplary Programs and Practices

The North Central Regional Information Exchange (NCRIE) is seeking nominations of programs and practices which are exemplary or innovative in their abilities to serve individuals with disabilities. NCRIE represents states in Region V: Illinois, Indiana, Michigan, Minnesota, Wisconsin, and Ohio. Nominations are sought in the following program areas: 1) interagency collaboration and coordination in programs on transition from school to work; 2) emergent issues in supported employment programs such as the use of natural supports, coworker involvement; and 3) parent-professional collaboration.

Send nominations by February 19, 1993. Contact: NCRIE, Institute on Community Integration, University of Minnesota, 6 Pattee Hall, 150 Pillsbury Drive, SE, Minneapolis, MN 55455. 612/624-4848.

## Resource

The National Information Center for Children and Youth with Disabilities (NICHCY) is a national information and referral clearinghouse available to anyone. NICHCY is a project of Interstate Research Associates, Inc., and is supported through a Cooperative Agreement with the U.S. Department of Education, Office of Special Education and Rehabilitative Services (OSERS). Services include: 1) personal responses to questions; 2) referrals to other organizations; 3) prepared information packets; and 4) technical assistance to family and professional groups. Free publications include: News Digest, a single issue newsletter which researches current topics regarding disabilities; and Transition Summary, which explores issues regarding the transition from school to adult life. Contact: NICHCY, P.O. Box 1492, Washington, D.C. 20013-1492. 1/800/999-5599 toll-free, or 703/893-8614 TDD.

*To the old ones of my childhood  
who taught me the most important  
lesson of all:*

*That I did not need to be perfect  
to be loved.*

*That no one does.*

Alice Walker, *To Hell With Dying*

## Never Say Never New Jersey's "Johnstone" Closes

by Marc Mercer

Ada Lippens, Cynthia's mother, is very pleased at the new opportunities in her daughter's life. "It's like a miracle from heaven," she told me in a recent interview. "I never thought that Cyndy would be able to do such things. I can't believe how she has changed. She has grown stronger both physically and emotionally. It just goes to show you—never say never."

On September 30, 1992, the last resident left Johnstone, a state-operated residence in New Jersey. Ada Lippens, like other Johnstone parents, was extremely upset by the closing and very fearful for her daughter's future.

"I have been a grandmother eight times and I had never been to a pumpkin patch," she said. "I don't know how to say this. This time of year, I understand, all the vines start to die and the pumpkins get bigger. Something has to die and go to the pumpkin. Johnstone had to close for this to happen. I am not sure that I can explain just what I mean. It's like the things that support us have to wither away sometimes before we can grow."

Yes, you read correctly. . . a pumpkin patch. I had gone to visit Community Options, founded by Bob Stack, and discovered a powerful demonstration of what you can do with a lot of imagination and some aspirations for people with developmental disabilities that stretch, rather than limit their potential. The pumpkin patch is where Cynthia participates in supported employment. At Johnstone, she had worked at the on-grounds workshop making pens and packaging small items. "I liked it okay, but, after 15 years, I wanted to leave," she said of her life at Johnstone. Asked about her current job, she says, "I love it. It's my job and I get paid for it." Cynthia is moving on. She has a job interview at Bradlee's in the near future.

I asked Mrs. Lippen if she thinks that Cyndy will ever live on her own. "Never say never," she reminded me.

It's society, really," she added. "Society needs to change. People are afraid of people who are different. I think that closing the institutions will change that. People will get to know them and will understand that there is nothing to be afraid of."

Marc Mercer is Senior Writer for the New Jersey Developmental Disabilities Council. This article appeared in a special feature edition about the closing of Johnstone, *People with Disabilities*, October 1992, Vol. 2, No. 4, p. 27. Contact: The New Jersey Developmental Disabilities Council, CN 700, 32 West State Street, Trenton, New Jersey 08625-0700. 609/777-3238.

## Realistic Survival Guide Published

Over a year ago, a group of disability rights activists met in a Seattle conference room for lunch and after months of work it seemed as if a book on self-advocacy was finally on its way. However, what could be said that had not been said before? "What B.S.!" said one man loudly and clearly, using his communication device. "What are we going to tell everyone? That the minute they speak up they'll move into the community, get a girlfriend and everything will be all right? That they'll have enough money? That no one will discriminate against them? That their case manager will automatically respect their opinion? Let's get real for once!" The result is a publication that is straight-shooting, myth bashing, tell-it-like-it-is real life called: *No More B.S.: A Realistic Survival Guide for Disability Rights Activists*. Price: \$10.00, payable to People First of Washington, P.O. Box 648 Clarkston, Washington 99403.

# United Nations Sets World Agenda on Disabilities

## Part Two in a Monthly Series

As part of the "World Program of Action Concerning Persons with Disabilities" (published in August 1992), the United Nations General Assembly outlined some of the following recommendations:

### Participation in Decision-Making

- Member States should increase their assistance to organizations of persons with disabilities and help them organize and coordinate the interests and concerns of persons with disabilities.
- Member States should establish direct contacts with such organizations and provide channels for them to influence government policies and decisions in all areas that concern them.

### Prevention

The technology to prevent and control most disabilities is available and improving, but is not always fully utilized. Member States should take appropriate measures for the prevention of impairment and disability and ensure the dissemination of relevant knowledge and technology. Coordinated programs should include:

- The establishment of primary health care systems in each community that will reach all segments of the population, particularly in rural areas and urban slums;
  - Effective maternal and child health care and counseling, as well as counseling for family planning and family life;
  - Education in nutrition and assistance in obtaining a proper diet;
  - Immunization against communicable diseases;
  - A system of early detection and early intervention;
  - Safety regulations and training programs for the prevention of accidents in the home, workplace, on the road and in leisure-related activities;
  - Measures to control the imprudent use of medication, drugs, alcohol, tobacco, and other stimulants or depressants in order to prevent drug-related disability, particularly among school children and people who are elderly. Of particular concern is the effect upon unborn children of imprudent consumption of these substances by pregnant women.
  - Educational and public health activities that will assist people in attaining lifestyles that will provide the maximum defence against the causes of disabilities.
- Note: Future issues of *Futurity* will list specific recommendations made in other areas, including: equalization of opportunities; legislation; physical environment; income maintenance and social security; education and training; employment; recreation; and culture.

## Publications

*Inclusion Resources, II*, Expectations Unlimited, Inc., Summer 1992. This bibliography of materials and resources concentrates on how everyone can be included in their communities. Selections, listed with costs, include: video productions, video conference/workshop presentations, and publications. Contact: Expectations Unlimited, Inc., P.O. Box 655, Niwot, Colorado 80544. 303/652-2727.

*Supported Employment: A Step-by-Step Guide*, PACER Center, Inc., 1992. This manual is intended for individuals and groups in Minnesota--understanding supported employment within the context of the service system, and how to gain access to it. It describes current "best practices," and suggests ways to get supported employment services started in your community. Available free to Minnesota young adults and adults with disabilities or their families. Price to others: \$8.00. Contact: PACER Center, Inc., 4826 Chicago Avenue, South, Minneapolis, MN 55417-1098. 612/827-2966 (voice and TDD).

## "Disability Rights Alliance" A New Name with Renewed Enthusiasm

After nearly 20 years as a leading organization in the movement for disability rights in Minnesota, the United Handicapped Federation has made a major change. At the Annual Meeting on November 14, the membership ratified a new name for the organization: "Disability Rights Alliance." This new name is the result of an intensive year-long planning effort. In addition, the newsletter *Progress* will now be called "Disability Rights Alert." The Disability Rights Alliance will continue strong activism in improving accessibility, monitoring transportation issues, and will seek to improve employment opportunities for all persons with disabilities. For more information, contact: Disability Rights Alliance, 1821 University Avenue, West, Suite 284-S, St. Paul, MN 55104. 612/645-8922 (voice and TDD); 612/649-3073 FAX.

## "DRAGnet" Electronic Information Service Created

There is now a new electronic bulletin board service in Minnesota called DRAGnet. The name stands for Disability Resources, Activities, and Groups Network, now made available through Disability Rights Alliance. The service can be accessed via a personal computer and modem, even for those requiring voice synthesizers, by calling 612/753-1943.

The idea for DRAGnet came from the simple desire to gather and share important disability-related information. It was created by Gordon L. Gillesby of Andover, Minnesota, who acquired a disability in 1989, and later compiled the first national survey of disability-related electronic bulletin boards, published in *Boardwatch Magazine*.

Dragnet is available 24-hours-a-day providing over 200 disability conferences, events, computer and recreational software, educational text files, newsletters, and forums for self-expression. DRAGnet is the outlet for national bulletin boards: ADAnet, Disability Law Foundation, and various Independent Living programs across the country. Plans are underway to expand DRAGnet and establish toll-free access throughout Minnesota.

Contact: Disability Rights Alliance, 1821 University Avenue, West, Suite 284-S, St. Paul, MN 55104. 612/645-8922 (voice and TDD); 612/649-3073 FAX.

## 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.

**Boards from Hell**, S.M. Scribner, Scribner and Associates, 1991. (Publication). Learning from what often goes wrong, nonprofit agency boards can build on strengths and create a "heavenly board" where members are: committed, involved, informed, clear about expectations, challenged, trained, and held accountable.

Two features on one videotape: 1) **Supported Employment: More Than Just a Job**, (26 minutes), stories of several individuals whose lives have been enriched through real work in New Hampshire; and 2) **A Waiting Workforce: Ready, Willing, and Disabled**, (26 minutes), National Center for Research in Vocational Education, Ohio, State University, emphasizes an untapped national resource and the potential of people with disabilities in the labor force.

Two features on one videotape: 1) **Family Support: A New Hampshire Legislative Victory** (12 minutes), depicts how parents and family members brought about the creation of a statewide system of family support services; and 2) **Closing the Doors and Opening the Windows**, (18 minutes), documents how New Hampshire became the first state in the nation to shift its resources to provide services in communities--the closing of Laconia Developmental Services on January 31, 1991.

### **Futurity is Available on Audio Cassette**

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

## McGill University Plans Eighth Summer Institute (July 5-16, 1993)

The Summer Institute in Integrated Education and Community is a university program for professionals, parents, and self-advocates interested in learning about integration; how to bring people with challenging needs into schools, workplaces, and communities. This is the eighth year that the McGill University of Montreal, Quebec has sponsored these two-week Summer Institutes.

Courses for 1993 include: Action for Inclusion--the Learning Community; Strategies for Day-to-Day in the Classroom; Working for People with Difficult Behavior; Building Communities of Diversity; Transforming School Culture--Strategies that Work; and Leadership Seminar in Systems Change. Faculty include: Marsha Forest, Judith Snow, Jack Pearpoint, John O'Brien, Evelyn Lusthaus, Gerry Cross, Shafik Abu Tahir, Joe Whittaker, Gordon Porter, Herb Lovett, John McKnight, Richard Villa, Jackie Thousand, and George Flynn.

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

## Become A Specialist in Supported Employment

Kaposia Works, Inc., of St. Paul has established a certified apprenticeship program for Supported Employment Specialists. A Certified Supported Employment Specialist trains, supervises, and supports individuals with disabilities on the job. This three-year learning experience was developed with the assistance of the Minnesota Department of Labor and Industry. Apprentices receive 6,000 hours of on-the-job training, plus 144 hours of additional class instruction related to supported employment. For more information, contact: Patty Peyer, Kaposia, Inc., 380 East Lafayette Freeway South, St. Paul, MN 55107-1216. 612/224-6974.

## Zero in Minnesota

*"I applied for Medicaid for my 13-year-old son. Eligibility is based on my son's income. His income is zero. We had to fill out an 18-page booklet that asked questions about family income which were irrelevant. I asked why did I have to fill out 18 pages when his income was zero? They said, 'We have no other forms so that's why we gave this to you.' I just received a three-page form for recertification asking what's his income. It's still zero."*

*Mother's Testimony at Town Meeting  
Minnesotans Speak-Out!, 1992*

## Futurity

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