
D**D****INFORMATION
EXCHANGE**

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**A NEW DECADE, THE 1990'S
BUILDING INCLUSIVE COMMUNITIES**

During the 1980's a lot of things began to happen to change services and to impact the lives of individuals with developmental disabilities in Minnesota and in many other places in our country. We discovered the word integration and began to apply it. Children with developmental disabilities began to attend regular education classes and it worked; adults with developmental disabilities found jobs with support in the regular marketplace and it worked; children and adults participated in team sports, scouting, church activities, and community park and recreation programs with their same-age peers and it worked. We've learned that it can work and it's not such a big deal that we thought it would be.

The challenge for us during the next decade is to build truly inclusive communities. These inclusive communities will provide acceptance for all people, support to live in the community, hope that lives will improve, love for one another, and caring that each individual will have a quality of life he or she deserves. People of color have not accepted separate but equal, and people with developmental disabilities should not accept it either. As we move through the next decade, there is clearly a lot of work yet to do to include all people with developmental disabilities as full participants throughout Minnesota. It will require

teamwork to assure that by the year 2000 there is no need to use the word "special" when referring to people with developmental disabilities. Below is an article written by a father in Macon, Georgia which expresses his thoughts on the use of the word "special."

SPECIAL

**by John Chandler, parent
Macon Georgia**

When I think of what is special in my life, it's very easy to list many things. My wife, kids and family, of course, come to mind. Next are my friends, both those in Macon, and those I've made in Georgia and around the country. My job is special for me. I enjoy my work and work with pleasant people. Traveling and meeting new people are also special for me.

There are other things in my life that are special. My home and yard are special. I enjoy minor home improvements and working in the yard. I enjoy movies and plays. And the beach and mountains are very special places for me.

People often refer to folks who experience developmental disabilities as "special." "Special" places and "special" activities are usually provided for these "special" people.

However, in my mind, these "special" places don't afford the possibilities for enjoyment and growth as the special places the rest of us choose. As a society we have

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decided that people with handicaps need us to decide what is "special" for them.

We have decided that large institutions with barred windows, locked doors, and congregate bathrooms and bedrooms are the best "special" places for some. We have decided that nursing homes are best for others. Many children are so "special" we want to selfishly keep them for ourselves, so we put them in programs that make sure no other "non-special" children get near. And when these children get older, they are so "special" that we bus them from one side of the country to the other so they won't have to spend time with "non-specials."

During the school years, we neglect to assist "special" people to get ready for adult work, because "special" people should not have to work like "non-specials." And, after graduation, we make sure that all the "specials" go to a new "special" place so that adult "non-specials" will not get too close. When we plan recreation, we are careful to make sure we have enough "specials" going so that they don't get bored and seek out "non-specials" for conversation. We also need to schedule recreation so it will occur at a time of day when "specials" will not interfere with fun for "non-specials."

The one thing I don't understand about this whole process of judging who or what is special is--why are special places different for "specials" and "non-specials?" Why do we "non-specials" choose one thing for our selves and something very different for our "special" friends? Perhaps the only way we will ever find out is to ask them.

SURVEY EVALUATION OF FUTURES PLANNING BOOK COMPLETE

During the late fall of 1989 the Metropolitan Council conducted a survey and completed a report on the publication, *"It's Never Too Early, It's Never Too Late"* a booklet about Personal Futures Planning. The booklet is targeted for persons with developmental disabilities, their families and friends, case managers, service providers and advocates.

Methodology

The universe consisted of 141 individuals in the Twin Cities Area who ordered the publication. Telephone numbers were obtained for about 60% of the universe and individuals were randomly chosen from the list with telephone numbers. The interviews were conducted between November 7 through November 14, 1989. Twenty-seven interviews were completed, representing 19 percent of the universe. Three persons refused to

participate.

Summary of Results

Most of the individuals who ordered the booklet were parents and/or professionals in the developmental disabilities field. Eight-two percent (22 people) had read the publication at the time of the interview.

Of the people who had read the booklet, all of them felt it was clearly written, ranking the booklet either a "4" or "5" on a five point scale. Similarly, 100 percent felt that the graphics and charts were effective in conveying the concepts in the book. In addition, most respondents felt that the photography and the colors were effective in conveying the messages in the booklet. Eighty-four percent said the book gave them a clear understanding of what Personal Futures Planning was. Of the three people who did not get a clear understanding of PFP from the booklet, two of them expressed a desire for more information to be included in the booklet. One hundred percent would recommend the book to others.

Eighty-four percent (16 people) pursued Personal Futures Planning (PFP) after reading the booklet, and did so in a variety of ways including attending seminars, talking to others, and telling others about the book. Ten people (53 percent) who had read the book had started PFP with an individual.

The people who had done Personal Futures Planning were in varying stages of the process, from just starting the plan to completely finished. All of the people who completed the profile meetings or planning meetings felt that the length of the meeting and the length between meeting were "just right." Of the five people who were further along in the process, all felt that the support group were effective in making changes and found positive changes in the target person since the PFP.

Most of the people (5 out of 6) said a part of the Person Futures Plan became part of the Individual Service Plan. Four out of five found that the PFP worked well in conjunction with the county case manager or other persons who had control over services used for PFP. Half of the people who answered the question (3 people) found that funding mechanisms were a barrier to PFP.

Eighty-three percent (5 people) felt that the PFP had an impact on community participation and 100 percent would recommend PFP to others.

Thanks to Laura Hutton, Data Center planner, and Christerfer Schultz, intern, for their invaluable assistance and support in conducting the surveys and preparing the report.

Copies of the booklet, *"It's Never Too Early, It's Never Too Late"* are available by writing to: Metropolitan Council Data Center, Mears Park Centre, 230 E. Fifth St., St. Paul, MN 55101. One to five copies will be mailed at no charge.

PARENTS WITH DIFFERENCES

The working mother of "normal" children screams at the kids and breaks into tears after a harried supper. She is said to be overworked and offered an evening on the town. The mother of a child with disabilities does the same. She is said to be emotionally upset and offered a psychiatrist.

A couple with "normal" children divorce. They are said to be incompatible. The parents of a child with disabilities divorce, and it is said that the child ruined the marriage.

A father says that someday his daughter will be the first woman president. It is said he is prideful. A father of a child with disabilities says that someday his daughter will walk. It is said he is unaccepting.

A group of "normal" children's parents read that a number of teachers and classes have been reduced and they bemoan the present state of education. Parents of children with disabilities read that their child's classes have been cut and they must march upon the legislature.

The parents of a "normal" child are told that because their child is having reading difficulty, it would be nice if they would work with her at home. The parents of a child with disabilities are told that if they don't work with their child at home she will not learn!

(An abridgment reprinted from "Pilot Parents in Action," Omaha, Nebraska)

EMPLOYMENT OPPORTUNITY

The Association for Persons with Severe Handicaps is recruiting a Project Director for a three-year project titled "How to Figure in One Another's Survival - A Grassroots Model to Develop Peer Support Networks for Workers with Severe Cognitive Delays." Salary is \$30,000 per year plus benefits. The grant will create systems of social networks for individuals already in supported employment. Over the next three years, we will develop social networks in nine sites. Candidates should have a Master's degree or equivalent experience in an area related to service delivery, research, training, or policy development of individuals with developmental disabilities; a minimum of five years experience in the

developmental disabilities field, including expertise in services for individuals with severe disabilities; project administration and in-service training; a working knowledge in social networking and the mechanics of supported employment for people with developmental disabilities; and a demonstrated commitment to a quality life for people with developmental disabilities. Send applications to Liz Lindley, TASH, 7010 Roosevelt Way N.E., Seattle WA 98115.

CONFERENCES/WORKSHOPS

January 10

Parent Advocacy Coalition of Education Rights (PACER) is sponsoring a workshop on computers featuring Dr. Bill Peet, a nationally-recognized innovator on using computers to help children with disabilities learn to read and write. The workshop will be held at the Minnesota Educational Computer Corporation (MECC), 3490 Lexington Av. N. in St. Paul from 4 to 9 p.m. Reservations are required by calling (612) 827-2966. A box lunch will be available for \$5.

January 11-13

The National Center for Outcome-Based Education is sponsoring a conference *"Beyond Separate Education: Creating Quality Schools for all Students."* The conference will present a vision, offer a decision making model, identify barriers to success, and demonstrate proven models of effectiveness. The conference fee is \$295. It will be held at the Crescent Hotel, 2620 W. Dunlap Av., Phoenix, Arizona. For further information contact the National Center for Outcome-Based Education at (602) 837-8752.

January 16

"Service Skills for Front Line Personnel" is a three-hour workshop offered by Wilder Foundation. Attendees will learn about the new service expectations for the 1990's, ten value-building ideas and techniques for effective service, how to recognize and respond to "service moments of truth", how to make a positive telephone impression, how to deal with difficult and angry callers and how to stay in control even with tough clients. The fee is \$60. Session #1 is from 9 a.m. to noon; session #2 is from 1-4 p.m. Both will be held in the auditorium of the Wilder Foundation, 919 Lafond Av., St. Paul. For more information, call (612) 642-2058.

February 23

"Systematic Assessment and Treatment of Mental Health Problems in People with Developmental Disabilities" is sponsored by the American Association on Mental

Retardation (AAMR). The featured speaker is Dr. Steven Reill, Professor of Psychology at the University of Illinois and the Director of the Illinois Institute for Developmental Disabilities. Fees are \$30 for AAMR members, \$40 for non-members and \$25 for students. The workshop will be held at the Drovers Inn, 701 S. Concord, South St. Paul from 8:30 a.m. to 4 p.m. Morning sessions will emphasize assessment and identification. Afternoon sessions will emphasize a variety of mental health issues, including residential selection for people with mental health problems, prevention of abuse of people with dual diagnosis and comprehensive treatment development. For more information, contact: Marianne Reich, ARC Suburban, (612) 431-3700.

March 2-5

The National Parent-to-Parent Conference, "Toward New Horizons," will be held at the Sheraton Grand Hotel in Tampa, Florida. Co-sponsors include Parent-to-Parent of Florida and the Beach Center on Families and Disability at the University of Kansas. Registration is \$65. For further information, contact Parent-to-Parent of Florida, 3500 E. Fletcher Av., Suite 225, Tampa, Florida 33613.

CINEMA ALERT

My Left Foot. This just-out film about Dublin's painter and writer, Christy Brown, pulls you inside the longings, frustrations, and rage caused by cerebral palsy. Much of it gets communicated through his only usable limb--his left foot. "The movie may tear you apart, but it's the story of a triumphantly tough guy who lived it up . . . (The New Yorker, November 27, 1989). Now appearing at the Lincoln Center Cinema in New York City, which means the film will be shown in at least on theater in most large cities.

PUBLICATIONS/RESOURCES

Computer Directory

The 1989 *Closing the Gap Resource Directory* is a 140-page guide to microcomputer-related products and services determined appropriate for use in computer applications in the disability field. It lists hardware and software vendors (listed with product names) and service organizations which can assist in the implementation of adaptive technology. The cost is \$12.50. It can be purchased by sending a check to: Closing the Gap, P.O. Box 68, Henderson, MN 56044.

Assessments

Assessment: Special Education Tests is a handbook for

parents and professionals that examines the special education tests used by schools to assess children. The 42-page handbook will help parents understand what kind of assessment their child is being given; what qualities the test evaluates; and what other assessments may be appropriate. The handbook was published by the Parent Advocacy Coalition for Educational Rights (PACER) and edited by E. Jean Hosterman, a school psychologist and licensed consulting psychologist. The tests included cover intelligence, speech/language, perceptual motor, adaptive behavior, diagnostic systems, reading, writing/speech, math, academic achievement, screening devices, personality, preschool and vocational/transitional measurements. Tests were selected on the basis of their current use in special education programs in Minnesota. To order the *Assessment Handbook*, send \$4 to PACER Center, 4826 Chicago Av. S., Minneapolis, MN 55417. For more information, call (612) 827-2966. In Greater Minnesota, call toll-free 1-800-53PACER.

Training in Autism

An instructional program in autism titled, "*Understanding People with Autism*," is available for staff training. The series is a video-based instructional package which was professionally produced to provide a concise overview of the autistic syndrome while developing critical staff skills. The materials have a realistic and practical approach and were designed to develop and expand staff skills in: behavioral observation and record keeping, planning for success, strategies for analyzing communicative functions of behavior, developing communication systems, and principles of program planning in community settings. The training series utilizes exercises, quizzes and a broad age range of real-life examples, to develop a better understanding of individuals with autism. It was designed with the flexibility to be used with a facilitator in small groups or self-directed by individual staff. This instructional program was developed by the Twin Cities Society for Children and Adults with Autism (TCSAC)/Outcomes, Inc. The training package included: Part 1--Introduction to Autism: Overview and Part 2--Introduction to Autism: Communication. Each part contains a 22-minute VHS video training tape, a facilitator's guide, participant guide/workbook, exercises and additional resource information. Price for the total package of materials is \$95 or \$48 for each separate tape. To order, send a check to TCSAC/Outcomes, Inc., 253 E. Fourth St., St. Paul, MN 55101. For more information on these or other workshop opportunities, call (612) 228-9074.

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ADVOCACY: TO WHAT SHOULD WE ASPIRE? SUNDRAM PROPOSES 'DOCTRINE OF EQUALITY'

Speaking at the Annual Conference of the Young Adult Institute on April 13, 1989, in New York City, Clarence J. Sundram (Chair of the New York State Commission on Quality of Care) shared his thoughts about future directions for all of us as we enter a new decade--the 1990s. The following excerpts are from an article: "Advocacy: To What Should We Aspire?," *Quality of Care*, (August-September 1989), pp. 6-7.

Litigation: A 'Clumsy Tool': "As a lawyer who has been involved in the field of mental disabilities, I have done my share of reading, thinking, and arguing about the concepts of 'rights' as they apply to people with mental disabilities. In the type of litigious society in which we live, court calendars are filled with cases arguing about . . . (peoples') rights. Underlying all this litigation is an enormous sense of frustration at the inability of large and expensive governmental systems to see each person as a unique individual, with his or her own human needs. As the historian, David Rothman, has so compellingly observed, despite the law books with requirements for individualization--witness the IEPs and IHPs and the like--the demands of convenience often reduce services to the lowest common denominator in actual delivery."

Creative lawyers have thus devised elaborate procedural concepts, laden with legal jargon and ritual, to achieve a rather simple objective--to force greater professional attention on the unique needs of each individual. Stripped of their embellishments, these legal arguments about rights with fancy names are nothing more than pleas for a recognition of human dignity--where humanity and ability are recognized first and disability placed in perspective; where the value of freedom, choice and a normal life are not sacrificed too casually, where respect for an individual's needs and wants shapes the governmental response."

"If what is at the root of our disenchantment with service systems is an absence of an appropriate sense of values about, and a respect for, basic human dignity,

or a systemic inability to actualize such values, then litigation is a clumsy tool. The legal process may be able to force people to act as if they care, but it cannot actually get them to care, and that makes all the difference."

"The struggle to create unambiguous legal duties often results in regulatory minutiae, which surrender the civilizing expectation of true human caring in exchange for a stark set of compliance measures."

Changing Practices/Expectations: "Whether out of strategic necessity or the absence of better alternatives, advocates, like clinical professionals, have often been guilty of measuring out the lives of their clients in coffee spoons, as T.S. Eliot would describe it. While clinical professionals devote enormous resources to elaborate measurements of minute gains in learning, advocates often content themselves with equally small improvements for large efforts, e.g., moving from a large institution to a smaller 'community' Intermediate Care Facility. To content ourselves with such 'progress' is to accept the legitimacy of public policies that continue to segregate and isolate people on the basis of their disability."

Just as the written civil rights laws are evolving to include disability along with race, sex, ethnic origin, as prohibited bases for governmental discrimination, so too should our practices and expectations change.

Lionel Trilling was right when he observed the inevitable progression by which the objects of our pity become the subjects of our concern and finally the victims of our coercion. He might have added that the process usually starts with labeling the objects, which helps strip them of some of their humanity to distance 'them' from 'us.' This process has been at work in our history of providing for people with severe disabilities. We have invested millions and billions of dollars in edifice complexes and, when they are proven irrefutably not to work, to brutalize rather than enrich the lives of the people they are intended to help. Our minds are so captured by this way of thinking that we can only think of alternative forms of institutions in which to contain them."

The only policy goal that is morally and ethically

defensible, and one to which I suggest we aspire,--equality in the treatment of people with disabilities. The test is simple: whatever we would not want for ourselves, we should not prescribe or adopt as public policy for people who are disabled. It seems to me that advocacy has to proceed from a bedrock belief in a notion of equality. If it is essential to the quality of our lives that we have the opportunity to form relationships with others, freely and by choice, we ought to promote similar opportunities for people with disabilities.

People with severe disabilities need the same chance at a normal life, with its risks and rewards. With the help of family or caring friends, imaginative professionals, and flexible government officials, people with a disabilities might be having their needs met in a normal home, with a natural or surrogate family, living with more freedom and dignity, with more opportunities to form and maintain real human relationships, to enrich their own lives and those of others around them.

"What needs institutional confinement, segregation and isolation is our own lack of imagination, courage and audacity to push public policy towards making this experience the norm, and segregated facilities, institutional or community, large or small, relics."

Reference Point for Equal Treatment: "I suggest that the reference point for equal treatment is the non-disabled citizen, with whom the person with a disability shares common legal rights and protections under the law. The notion of equality ought to recognize the intrinsic equal worth of a human life, and not merely its capacity to produce goods or services. We share a common ability to learn and to teach, to experience emotions, to enjoy friendship, to give and to receive."

"All of you must raise your voices and your expectations. There is a need to change practices that have out-lived their defensibility, to erode the general acceptance of segregation of people with disabilities as neither arbitrary nor irrational. In short, we must do better to articulate 'the evolving standards of decency that mark the progress of a maturing society.'"

For complete copies of the address, and for further information, contact: Editor, Quality of Care Newsletter; Commission on Quality of Care for the Mentally Disabled; Suite 1002; 99 Washington Avenue; Albany, NY 12210-2807.

1990 REPORT RELEASED

The Governor's Planning Council on Developmental

Disabilities is proud to announce the availability of its 1990 Report: *The Heart of Community Is Inclusion*. .. This report reviews issues of eligibility for services, critical issues for the 1990s, achieving accountability to those who use services, and ways of empowering individuals with disabilities. Copies will be sent to those on our mailing list. Inquiries and orders should be directed to: Governor's Planning Council on Developmental Disabilities; 300 Centennial Office Building; 658 Cedar Street; St. Paul, MN 55155. Tel. (612) 296-4018, or (612) 296-9962 (TDD).

ASSISTANCE REQUESTED FOR RESPITE CARE STUDY

The Department of Human Services is requesting information about caregiver support/respice care services in preparation of reports to the 1990 and 1991 Legislatures. "Respice care" is defined as "planned or emergency care provided to persons who are elderly or have a mental and/or physical disability, in or out of the home, for the purpose of providing relief to the family from the daily responsibilities of caring for their family member."

The following information is needed:

What types (public and private) of caregiver support/respice care services are currently available to Minnesota citizens?

Who and how many people are now receiving or are in need of such services?

What are the sources of funds available for providing respice care services?

What are the personal and financial benefits that could be realized through the provision of an expanded or improved system of respice care services, such as could respice care services forestall or avoid placement of people in more restrictive settings, such as nursing homes or other out- of-home placements?

What is the quality of respice care services, such as, are providers of these services adequately trained, compensated, and supervised?

Personal stories or experiences are also being requested. Such testimony can be helpful to the legislators to better understand some of the implications behind the data that are collected in this study.

Please send information, publications, brochures, etc. to:
Nancy Smith; Respice Care Specialist; Minnesota Department of Human Services; 444 Lafayette Road;

PUBLICATIONS/RESOURCES

Action for Inclusion: How to Improve Schools by Welcoming Children with Special Needs into Regular Classrooms, by John O'Brien, Marsha Forest, with Judith Snow and David Hasbury, Centre for Integrated Education, Toronto, 1989. The authors provide this guide within a premise that "Good schools get better when they include all the children in the school's neighborhood . . . good teachers grow stronger . . . students develop more fully . . . and families get stronger when they join teachers and students to create classrooms that work for everyone. Inclusion is the right thing to do." "Like any change resulting in greater social justice, Action for Inclusion demands new learning and hard work. The practical lessons in this manual--distilled from five years work in good, ordinary classrooms--outlined these demands and share what we (the authors) have learned so far about how to meet them." This is a guide that the authors intend to "begin the journey of integration." Available from: Frontier College Press, Centre for Integrated Education, 35 Jackes Avenue; Toronto, Ontario, Canada M4T 1E2.

Integration Strategies for Students with Handicaps, by Robert Gaylord Ross, is a textbook that describes various methods for integrating students with disabilities into regular school and social environments. It addresses strategies for working with students with specific disabilities as well as cultural differences. The text includes innovative techniques in vocational training and the use of microcomputer technology. A major section is devoted to "the ecology of service delivery." Available for \$35.00 from Paul H. Brookes Publishing Company; P.O. Box 10624; Baltimore, MD 21285. Tel. (301) 337-9580.

International Directory of Mental Retardation Resources, Third Edition, 1989, authored by Rosemary Dybwad. This resource provides a summary of the major programs for persons with mental retardation and other developmental disabilities in over 80 countries. The Directory will assist organizations and agencies throughout the world to communicate with each other in order to share their knowledge and research findings. Available from the publisher: The President's Committee on Mental Retardation, U.S. Department of Health and Human Services, Office of Human Development Services, Washington DC 20201.

Aging and Lifelong Disabilities: Partnership for the Twenty-First Century--the Wingspread Conference Report, E. F. Ansello and T. Rose (Eds.), University of Maryland Center on Aging, 1989. This conference report

summarizes presentations by leaders in the fields of developmental disabilities and aging. The conference agenda focused on visions for the future and practical plans of action. Copies of the report cost \$10 from: National Center on Aging and Disabilities; Center on Aging; University of Maryland; College Park, Maryland 20742-2611. Tel. (301) 454-5856.

PARENT CASE MANAGEMENT TRAINING SCHEDULED

A series of training sessions entitled "Self-Determination and Empowerment for Persons with Developmental Disabilities" have been scheduled in Greater Minnesota areas. This training is part of the Parent Case Management Project of the Minnesota Institute on Community Integration at the University of Minnesota, which is funded under a grant from the Governor's Planning Council on Developmental Disabilities. Co-sponsors include: Pilot Parents of Minnesota and Southwest/West Central Educational Cooperative Service Unit. The intent is to empower individuals to participate more fully in the case management of services. It is designed for parents, guardians, persons with disabilities, case managers, advocates, and others. Session One relating to "Case Management" and "Rules and Regulations" will be from 9:00 a.m. to 4:30 p.m. as follows:

February 3, 1990--Bemidji--Technical College
February 10, 1990--Marshall--SW State University
February 24, 1990--Hibbing--Technical College

For a complete schedule of future training and for registration, contact: Marijo McBride, Institute on Community Integration; University of Minnesota; 6 Pattee Hall; 150 Pillsbury Drive, S.E.; Minneapolis Minnesota 55455. Tel. (612) 624-4848.



The State Developmental Disabilities (DD) Program Office has acquired several education, training and resource materials. The following materials may be borrowed from the State Office only, located at the address on the front sheet of the State Supplement section of this newsletter. Tel. (612)296-4018.

LENDING LIBRARY SELECTIONS

Policy Implementation and P.L. 99-457: Planning for Young Children with Special Needs, J.J. Gallagher, P.L. Trohanis, & R.M. Clifford (Eds.), Paul H. Brookes Publishing Company, 1989. This volume presents many of the significant issues that have emerged that will affect the implementation of federal legislative initiative, Part H of Public Law 99-457, the Education for All Handicapped Children Act Amendments of 1986. Under this legislation, funds are provided by the federal government to cover the states' planning and development, with 4 years to develop their plans to meet the broad directive of serving all eligible children, birth to 3 years of age. Contributors explore the effect of policy implications on family concerns, personnel preparation, interagency planning, and public and private funding. Also available (Price: \$28.00) from the publisher: Paul H. Brookes Publishing Company; P.O. Box 10624; Baltimore, Maryland 21285. Tel. (800) 638-3775, toll-free.

Respite Care: Support for Persons with Developmental Disabilities and Their Families, C.L. Salisbury & James Intagliata, Paul H. Brookes Publishing Company, 1986. This book provides practical information presented against a background of theory and research supporting the need of respite services. "Respite care" is defined as services provided to families to enable them to take a break from the responsibility of caring for a member with a disability. Finding ways to support families means healthier and more integrated environments of persons with disabilities. Contents are organized into three major sections: (1) rationale and need for respite services; (2) issues and models for delivering respite services; and (3) evaluating respite services.

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If you no longer wish to receive this newsletter,
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A NEW DECADE, THE 1990S: BUILDING INCLUSIVE COMMUNITIES

During the 1990s we will hear more and more discussion about quality concerns. Those discussions in the '80s focused primarily around quality of care--the homey appearance of a group home, the nutritional value of food, the square footage of rooms, the contents of first-aid kits, the writing of Individual Habilitation Plan goals and objectives. An important development in the '80s was supports to families to enhance their quality of life and take care of their own child with disabilities within their own home. The waiver allowed some people to live in more individualized homes. Increasing numbers of adults moved into supervised apartments. We began to use "People First" language, recognizing that people are people first and have a disability second. Children with severe disabilities began to find acceptance in classes with regular kids, and adults and teachers had experiences that demonstrated to them that integrated education works.

During the next decade we will see the focus on quality shift to a stronger emphasis on individuals rather than on physical things and paper. The new focus will place a higher value on what it is the individual wants for his or her life that will make them happy, content, active in their community, and in control of the direction of their life. The new focus will place a lower value on what providers, teachers, psychologists and other professionals want or insist people with disabilities to learn and

participate in. In short, we will give people with disabilities a choice. Human service workers will begin to pay more attention to people with disabilities and to their families, friends and advocates who all have a lot to say about what they desire for a future for the person with a disability. We will put our efforts not only into finding out what it is a person chooses to do now and in the future, but also to finding ways to make it better and better. In this way people with developmental disabilities can attain their own self-actualization.

"*Support*" will be the leading word for the next several years. Families, teachers and other service providers will look not for ways to teach, reinforce, instruct or change individuals, but for ways to support individuals in attaining the goals and aspirations they have for themselves. First of all, *Support* involves finding out what it is a person desires and then devising every means possible for them to move in the direction of that choice. It means providing encouragement and other physical and emotional sustenance. Accommodations will need to be made to support the individual in accessing all aspects of community life. *Support* will be the important concept in the '90's to enable people with developmental disabilities to attain full participation in society. The challenge to all of us who know people with developmental disabilities is to discover the possibilities to help them achieve it.

One of our nation's leaders in discussing quality issues is Hank Bersani, Jr. who is with Community Integration Associates in Manilus, New York. He has developed an

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"integration report card for residential services" for both children and adults. He grades services in a report-card fashion--A to F. Residential services are to be graded in two major areas--current level of practice of integration and current level of values that are supportive of integration. How do residential services you know measure up to the "report card" below? What could you do to move that residential service to a better grade?

Grade A

Practice: All children live with families. Adults live in groups that reflect the size of their homes in the community.

Values: Community living is seen as valuable for all people.

Grade B

Practice: There are no large, congregate, segregated settings. Plans exist to close or downsize the few remaining "large" community settings (six people and over).

Values: Small settings are valued, especially for children and people with the most severe handicaps.

Grade C

Practice: There are plans to close remaining group settings for children. Efforts are underway to "downsize" settings for 15 people or more.

Values: Small size is valued, but concerns persist about the economic and practicality of very small settings.

Grade D

Practice: A moratorium is in effect in the development of larger (more than "x" people) settings. Alternatives are being explored.

Values: There is an openness to the possibility of some integrated living for some people. Care must be taken not to move people into community settings when it will be inappropriate.

Grade F

Practice: Plans exist to expand congregated, segregated living options. Plans include

group homes for children and large specialized settings for adults.

Values: Segregated living is seen as a value for people with various disabilities, and as a part of a segregated system relying on education and work options.

For more information, contact: Hank Bersani, Jr. Community Integration Associates, 4508 Watervale RD., Manilus, NY 13104.

CREATING A WELCOMING ENVIRONMENT FOR PEOPLE WITH DISABILITIES OF ALL AGES

"People with disabilities have to struggle to make environments welcoming to them," said Judith E. Heumann, M.P.H. at a lecture recently sponsored by the School of Social Work at the University of Minnesota. Ms. Heumann is the vice president and co-founder of the World Institute on Disability, a non-profit, public policy, research and advocacy center in Berkeley, California. A leading activist in the disability movement, Ms. Heumann says one of her goals is to further the gains made by the independent living and civil rights movement for people with disabilities so that throughout the world, regardless of age or the severity of their disability, they can lead productive, proud lives in integrated environments.

"Creating a Welcoming Environment for People with Disabilities of All Ages" was the title of her presentation. People with disabilities don't want to be seen as special, she said, but that's difficult when the public and services make it so difficult not to be seen as special. People with disabilities want to be seen as having rights, the same rights as everyone else and that they should be able to do anything everyone else does.

A welcoming environment is a place where a person feels comfortable and where a person does not experience a lot of obstacles. To create a welcoming environment, people with disabilities need to work together, that is, people with and without disabilities need to work together to make it happen.

Seventy percent of people with disabilities aren't working, and of that 70 percent, half of those want to work, but there is a lot of discrimination present today. Many people without disabilities are afraid of becoming disabled, view being disabled as a devalued state, and prefer not to be around people with disabilities because it reminds them of their own vulnerability. Ms. Heumann cited a survey which further emphasizes discrimination in our society. In the survey, 93 percent of people surveyed said they would work with someone

in a wheelchair, but only seven percent would marry someone in a wheelchair.

NEW MEMBERS APPOINTED TO METROPOLITAN COUNCIL'S DEVELOPMENTAL DISABILITIES ADVISORY COMMITTEE

Three new members were recently appointed by the Metropolitan Council to its Developmental Disabilities Advisory Committee, a 25-member body which studies and recommends actions and policy statements related to developmental disabilities, to the Metropolitan Council. The new members are:

Twyla Misselhorn, District 6. Twyla is assistant administrator at Homeward Bound in New Hope.

Mary Piggott, District 14. Mary is technical assistance program director for the Institute for Disabilities Studies at the University of Minnesota.

Jack Stoehr, District 7. Jack is a supervisor in the Roseville office of the Minnesota Department of Rehabilitation Services.

FOR YOUR INFORMATION

Annual Award to be Given

Catholic Charities, within the Archdiocese of St. Paul and Minneapolis, annually gives an award to provide recognition to a person or a program which has demonstrated success in enriching the dignity of persons with disabilities within the Catholic community. Preference will be given to people or programs involved in advocacy and social change. The award was initiated in 1989 to honor a pastoral statement by the U.S. Bishops Conference in which church communities are challenged to provide access and programs for persons with disabilities. To receive further information and a nominating form, call Mary Jane Steinhagen at (612) 222-3001, or write her at Catholic Charities, 215 Old Sixth St., St. Paul, MN 55102. Nominations must be postmarked by March 31, 1990.

Mothers' Retreats

The ARC of Hennepin County is sponsoring five retreats for mothers. The retreats begin Friday evening and end Sunday afternoon. The cost is \$50 for ARC members and \$65 for non-members. There are two locations. There will be three retreats at Eden Wood Camping and Retreat Center in Eden Prairie in February for mothers with preschool to school age

children; April 27-29 for mothers of infants to preschool children; and May 18-20 for mothers of school age kids to young adults. Two retreats will be at the ARC Retreat Center in Cambridge, MN for those wanting a more restful contemplative focus. On March 16-18 the focus will be on "Rest and Reflection" and on Sept. 14-16, "Life Beyond Coping." For further information, contact: ARC of Hennepin County, 2344 Nicollet Av. S., Minneapolis, MN 55404 or (612) 874-6650.

Coalition for Integrated Education

SAFE is a national coalition of families, consumers and advocates that have united in an effort to promote the availability of educational services to all students, regardless of disability, at the school they would normally attend if they were not disabled. It advocates the following:

SAFE believes that all public schools should be both physically and programmatically accessible to all students within its geographic boundaries.

SAFE believes that all students, regardless of the severity of the disability, be provided with the necessary staff, space, equipment and assisting technology needed to provide an individualized and appropriate education on regular age-appropriate school campuses.

SAFE believes that for those students requiring some temporary services outside of the regular classroom, that those services be physically located to facilitate maximum opportunities for interaction between students with and without disabilities.

SAFE believes that the ratio of special education students to regular education students should not exceed that of the incidence of disabilities in the general population.

SAFE believes that though there may be situations in which the best setting for a particular student may be in places other than the home, separate campuses or other settings that isolate students with disabilities are never appropriate.

SAFE believes that integration should be approached as a value and the underlying philosophy by which we educate all students. We believe that successful integration depends on reconceptualizing teacher education programs so that all teachers are prepared to work with a wide range of students in integrated settings. The educational preparation of teachers should emphasize the elimination of traditional separation between "regular" and "special" education and should stress the shared responsibility of all teachers for all students.

SAFE believes that successful integration is dependent on the ongoing share responsibility of all teachers.

SAFE believes that all students are best educated in settings which are heterogeneous in all ways and that efforts to create "safe" environments for students with disabilities are consistent with larger school reform efforts which seek to make schools inclusive and responsive to all students.

For more information about this group and the work it is doing, contact: Marilyn, R. Wessels, 1305 Van Antwerp Apts., Gatehouse, Schenectady, NY 12309 or (518) 455-2096.

CONFERENCES/WORKSHOPS

February 23

"Systematic Assessment and Treatment of Mental Health Problems in People with Developmental Disabilities" is sponsored by the American Association on Mental Retardation (AAMR), Minnesota Chapter. The featured speaker is Dr. Steven Reiss, professor of Psychology at the University of Illinois and the director of the Illinois Institute of Developmental Disabilities. Fees are \$30 for AAMR members, \$40 for non-members and \$25 for students. The workshop will be held at the Drover's Inn, 701 S. Concord, So. St. Paul from 8:30 a.m. to 4 p.m. Morning sessions will emphasize assessment and identification. Afternoon sessions will emphasize a variety of mental health issues, including residential selection for people with mental health problems, prevention of abuse of people with dual diagnosis and comprehensive treatment development. For more information, contact: Marianne Reich, ARC Suburban, 14451 Co. Rd. 11, Burnsville, MN 55337 or (612) 431-3700.

March 2-5

The National Parent-to-Parent Conference, *"Toward New Horizons,"* will be held at the Sheraton Grand Hotel in Tampa, Florida. Co-sponsors include Parent-to-Parent of Florida and the Beach Center on Families and Disability at the University of Kansas. Linda Rother, chairperson of the Metropolitan Council Developmental Disabilities Advisory Committee, and Kay Zwernik, senior planner in developmental disabilities for the Metropolitan Council will present a session on Personal Futures Planning at the conference. Sessions stress parent involvement and decision making, family supports, health issues, networking, legal rights, transitions, parent organizations and more. Registration is \$65. For further information, contact: Parent-to-

Parent of Florida, 3500 E. Fletcher Av., Suite 225, Tampa, FL 33613.

February 15

The Parent Advocacy Coalition for Educational Rights (PACER) is sponsoring a workshop for parents of infants, toddlers and preschoolers with special needs and are eligible to receive early intervention services. These children can receive help through their local school district and other agencies (service providers.) This workshop will have the opportunity to hear how the system works, gain tips on getting good services, find out about assessments and learn how to communicate with professionals. The workshop will be Feb. 15 from 7 to 9 p.m. at the Eisenhower Community Center, 1001 Highway 7, Hopkins, MN. There is no fee. To register, contact: PACER, 4826 Chicago Av. S., Minneapolis, MN 55417 or (612) 827-2966 voice and TDD.

February 23-25

The *"10th Symposium on Management of Persons with Multiple Handicaps"* is a multidisciplinary conference for service providers helping people of all ages with profound handicaps. The conference will be held at the Radisson Hotel St. Paul, 11 E. Kellogg Blvd., St. Paul MN. Nineteen sessions, some of which are repeated, will be offered. Topics include ball therapy, nonlinguistic skill acquisition, positioning, specific treatment techniques, sensory integration, assessment, augmentative communication and others. Fees vary on the number of sessions attended. Group discounts and continuing education credits are available. For a brochure and further information, contact: Eileen Richter, OTR, 12015 N. July Av., Hugo, MN 550938.

March 8-9

"Education is Changing, Are We?" is the theme of the 33rd Annual Minnesota Council for Exceptional Children Conference to be held at the Sheraton Inn Northwest (Highways 694 and 81, Brooklyn Park). The conference is cosponsored by Minnesota Council for Children with Behavior Disorders and the Minnesota Council for Administrators of Special Education. Contact: Judy Rottsolk: (612) 222-2673, work; or (612) 345-2943, home.

INFORMATION EXCHANGE

STATE
SUPPLEMENT
February 1990

Developmental Disabilities Program
300 Centennial Office Bldg.
658 Cedar St.
St. Paul, Minnesota 55155

Minnesota State Planning Agency
Roger Strand, *Editor*
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GOVERNMENT SHOULD ENCOURAGE PEOPLE TO WORK, NOT GIVE 'TICKETS OUT OF THE WORKFORCE,' SAYS DISABILITY ADVISORY COUNCIL

A final report was recently released by the Disability Advisory Council of the Social Security Administration. Their study and recommendations addressed the medical and vocational aspects of disability legislation under both Title II and XVI of the Social Security Act--Disability Insurance (DI) and Supplemental Security Income (SSI). Three areas studied were: (1) the effectiveness of vocational rehabilitation programs for Social Security and Supplemental Security Income beneficiaries; (2) the question of using specialists to complete medical and vocational evaluations at the State agency decisionmaking level; and (3) alternative approaches to work evaluations.

"Many of the problems in the DI and SSI programs are interconnected," the Council stated. "We do not believe that DI and SSI programs for people who are disabled or blind should function as programs of premature retirement or as 'tickets out of the workforce.' Instead, they should operate on the principle that many people with disabilities, if provided with timely and appropriate services, can work and that they should be encouraged to do so. Fundamental features of these programs militate against these goals."

"Confusion is most keenly felt by people with disabilities themselves. To qualify for benefits, they are obliged to prove that they are incapable of gainful employment. The process of establishing such a claim can be long and cumbersome. Such a process may be debilitating by itself because the person is certified disabled by the agency and labeled incapable of work by all concerned. Once awarded benefits, he or she is told that regular and substantial earnings will cause payments to be suspended or terminated; yet he or she may also be referred for vocational rehabilitation services. **Beneficiaries are thus sent mixed signals--they must prove that their impairments -prevent them from working for at least 12 months in order to be awarded benefits; then they are encouraged to return to work**

and forfeit their benefits."

"The Council believes," the report continues, "that the Social Security Administration's current vocational rehabilitation (VR) programs have a negligible impact on increasing the capacity of SSI and DI beneficiaries to work or return to work. Thus, maximum savings to the trust funds/general revenues from the provision of VR services are not being realized. Many beneficiaries who have the potential for gainful employment are not being enrolled in VR programs. As a result, they are being denied the means with which to improve the quality of their lives."

Significant problems identified and recommendations made by the Advisory Council included:

1. "SSA does not routinely gather experiential data upon which to validate its current VR referral criteria. It is essential that such data be gathered and analyzed in order to improve the cost-effectiveness of the Social Security Administration's VR program."
2. "SSA does not maintain any direct management control over its VR programs, except through the reimbursement process. It is imperative to track persons referred by the Disability Determination Service (DDS) units for VR services in order to see if such services are actually requested or provided and to ensure that benefits are suspended to recipients who refuse to participate in VR programs without good cause. SSA should evaluate either periodically or on an ongoing basis the quality and cost-effectiveness of VR services provided."
3. "Differences in the goals of SSA's and the Federal-State VR programs must be recognized. State VR agencies wishing to be reimbursed by SSA for services rendered must assure that their VR programs for SSA clients that are referred by DDS units are geared towards the provision of services which achieve and maintain gainful employment. Further, DI and SSI applicants referred by DDS units to State VR agencies should be afforded the highest service priority by the Federal-State VR system."
4. "SSA's present system for VR referral and reimbursement promotes neither competition among

service providers nor the involvement of employers and unions in the formulation of job goals, the identification of job requirements and job skills. SSA should promote active competition among public and private agencies and should involve employers and unions in the planning and delivery of VR services for DI and SSI beneficiaries."

Regarding the recommendations in the report, the Council explained that they were "frustrated by the lack of data that are essential to the formulation of sound policy." "For this reason," the Council continued, "we refrained from developing recommendations that would fundamentally restructure these programs. Instead, we have recommended that SSA undertake demonstration projects that are comprehensive and that test a set of proposed changes. The agency should also sponsor research projects to examine various alternatives to the current DI and SSI programs."

Copies of the *Report of the Disability Advisory Council* may be requested from: Disability Advisory Council; Social Security Administration; Department of Health and Human Services; PO Box 17064; Baltimore, Maryland 21203.

REQUEST FOR PROPOSALS RELEASED BY PLANNING COUNCIL ON DEVELOPMENTAL DISABILITIES

The Governor's Planning Council on Developmental Disabilities recently published a Request for Proposals (RFP) that would address the following priority of the Council: "To increase the independence, productivity, and integration into the community of individuals by increasing the accountability of the community service providers, parents and advocates, generic agencies, and citizens."

Applications are due in the Council office no later than 4:30 p.m. on March 16, 1990.

For a copy of the RFP and application forms, contact: Ron Kaliszewski; Governor's Planning Council on Developmental Disabilities; 300 Centennial Building; 658 Cedar Street; St. Paul, MN 55155. Tel. (612) 296-4018 (voice), or (612) 296-9962 (TDD).

SUPPORT FOR CHANGE IN MEDICAL ASSISTANCE DENTAL PROGRAM SOUGHT

Information is being gathered to propose legislation to change the Medical Assistance Dental Program for some people who need fixed dental work.

A subcommittee of the Public Policy Committee of the Minnesota Governor's Planning Council has been studying the issue of restrictions in the Medical Assistance Dental Program which adversely affect persons with disabilities. There is a prohibition against cast metal restoration (crowns and bridges) dental work for people on Medical Assistance, a provision which was excluded from payment by Minnesota Statute in 1981.

Because of physical or mental impairments, some people are inhibited from participating in dental hygiene activities which are necessary if less expensive alternatives to cast metal restorations are supplied. In some situations, metal crowns or bridges, although more expensive initially, represent a cost effective service in the long run. A fixed bridge may also be safer than a removable prosthesis which may be broken, lost, or swallowed by some individuals.

If you or someone you know could benefit from fixed crowns or bridge work and have been unable to obtain them because of the prohibition in the Medical Assistance Program, please write about your situation to: Anne Henry; Legal Advocacy; 222 Grain Exchange Building; 323 Fourth Avenue South, Minneapolis, MN 55415.

PUBLICATIONS/RESOURCES

Community Transition Interagency Committees: Yearly Summary, Interagency Office on Transition Services, Minnesota Department of Education, 1989. This report highlights significant progress that over 80 Community Transition Interagency Committees throughout Minnesota have made during the past year. Created by the 1987 Legislature, these local committees have progressed from initial organizing efforts to actively improving local conditions through interagency planning and cooperation. State and local leadership has successfully drawn attention to the importance of interagency cooperation for the purpose of assisting students with disabilities as they leave school to seek independent living, vocational training, and employment. Available from: Minnesota Curriculum Service Center; 3554 White Bear Avenue; White Bear Lake, MN 55110. Tel. (612) 770-3943; or (800) 652-9024.

Guidelines and Recommended Practices for the Individualized Family Service Plan; National Early Childhood Technical Assistance System and Association for the Care of Children's Health (ACCH); Washington, DC, 1989. The Individualized Family Service Plan (IFSP) represents the cornerstone of the entire system of early intervention services provided under Part H Early Intervention Program for Handicapped Infants and Toddlers of Public Law 99-457. This set of recommended best practices are a result

recommendations made by the IFSP Task Force (May 1988), including: philosophy and conceptual framework, building positive relationships between professionals and families, identifying child and family strengths and needs, developing outcomes, and implementation. Available at a cost of \$15.50 (call regarding price of multiple copies) from: ACCH; 3615 Wisconsin Avenue, NW; Washington, DC 20016. Tel. (202) 244-1801.

1989-1990 Audiovisual Resource List, American Academy of Pediatrics. Over 100 videotapes on this resource list have been reviewed by the Academy and deemed suitable for use in the office or meetings with the public. Some of the topics include: accident prevention, adolescence, AIDS, child abuse, child development, disabilities, newborn care, nutrition, physical fitness, pregnancy, sex education, and substance abuse. The Resource List is available at the cost of \$7.50 each for members and \$10.00 each for nonmembers, plus \$3.75 shipping/handling. Send prepayments payable to: American Academy of Pediatrics; Publications Department; 141 Northwest Point Blvd.; P.O. Box 927; Elk Grove Village, IL 60009-0927.

Traveling Library Kits on Brain Related Topics: The Josephine Kretsch Brain and Body Resource Library, operated by A Chance to Grow, provides kits of 15-20 books and resource materials to libraries and organizations nationally. This service is free for libraries. Individuals and organizations may access this service through annual membership fees--\$25 for individuals, and \$50 for organizations. The kits provide valuable information for families and professionals about brain injury and related issues. Each kit also includes display materials. Kits are sent one-at-a-time for a 6 week loan period. Postage is paid one way. Examples of topics covered include: autism, cerebral palsy, children's books about disabilities, computers and disabilities, developmental disabilities, Down syndrome, epilepsy and seizures, and health and alternative care. Request order forms from: Josephine Kretsch Brain and Body Resource Library; 5034 Oliver Avenue North; Minneapolis, MN 55430. Tel. (612) 521-4245.

TRAINING IN PERSONAL FUTURES PLANNING SCHEDULED

The Human Services Research and Development Center (HSRCD) will be conducting a series of two-day training sessions in three regions of Minnesota. Under a grant from the Governor's Planning Council on Developmental Disabilities, these two-day sessions are essentially a continuation of a six-month course in learning how to conduct the development and completion of individual Personal Futures Plans.

Applicants should have some familiarity with the basic principles of Personal Futures Planning. Training sites are as follows:

Feb. 28-March 1 Thief River Falls (Alternate sites: Crookston, Moorhead);

March 7-8 Willmar (Alternate sites: Marshall, Alexandria, Fergus Falls);

March 21-22 Duluth

Alternate sites will be selected depending on the home-town location of the majority of the selected applicants. For more information and application forms, contact: Pat Lyon; HSRDC; 357 Oneida Street; St. Paul, MN 55102. Tel. (612) 227-9117.

PARENT CASE MANAGEMENT TRAINING SCHEDULED

The second session within a training series entitled "Self-Determination and Empowerment for Persons with Developmental Disabilities" has been scheduled. This training is part of the Parent Case Management Project of the Minnesota Institute on Community Integration at the University of Minnesota, which is funded under a grant from the Governor's Planning Council on Developmental Disabilities. Co-sponsors include: Pilot Parents of Minnesota and Southwest/West Central Educational Cooperative Service Unit. The intent is to empower individuals to participate more fully in the case management of services. It is designed for parents, guardians, persons with disabilities, case managers, advocates, and others.

Session Two relating to current philosophies and practices, transition, integration, advocacy and empowerment techniques, and use of resources will be from 9:00 a.m. to 4:30 p.m. as follows:

April 7, 1990 Bemidji--Technical College

April 28, 1990 Marshall--SW State University

May 5, 1990 Hibbing--Technical College

For a complete schedule of future training and for registration, contact: Marijo McBride, Institute on Community Integration; University of Minnesota; 6 Pattee Hall; 150 Pillsbury Drive, S.E.; Minneapolis, MN 55455. Tel. (612) 624-4848.

The State Developmental Disabilities (DD) Program Office has acquired several education, training and resource materials. The following materials may be borrowed from the State Office only, located at the address on the front sheet of the State Supplement section of this newsletter. Tel. (612)296-4018.

LENDING LIBRARY SELECTIONS

Disability and the Family: A Guide to Decisions for Adulthood; H. Rutherford Turnbull III, Ann P. Turnbull, G.J. Bronicki, Jean Ann Summers, and Constance Roeder-Gordon (Eds.); Paul H. Brookes Publishing Company, 1989. This volume provides guidelines for making plans that are legally and financially effective, that consider real-life choices and preferences, and that take into account the social, leisure, residential, and vocational options that can help ensure a desired quality of life for persons with disabilities and their families. Section I explores the meaning of mental competence and legal issues based on the person's ability to make decisions. Part II provides information about government benefits that can help to implement plans. Section III discusses the concept of choice and how individual preferences relate to interpersonal relationships and selection of residences, jobs, and leisure activities. Section IV provides a discussion of how to encourage people to be their own advocates. The authors maintain that future planning can improve the quality of life for all family members.

The Syracuse Community-Referenced Curriculum Guide for Students with Moderate and Severe Disabilities; Alison Ford, Roberta Schnorr, Luanna Meyer, Linda Davern,

Jim Black, and Patrick Dempsey (Eds.); Paul H. Brookes Publishing Company, 1989. Designed to serve students from kindergarten through age 21, this field-tested curriculum presents three major content areas for preparing students to function in the real world: community living domains--essential activities toward overall success and adaptability; functional academics--using the 3A's, adaptability, alternatives, and accountability; and social, communication, and motor skills as related to developing goals and objectives in a student's program.

The Syracuse Curriculum Revision Manual: A Group Process for Developing a Community-Referenced Curriculum Guide; Roberta Schnorr, Alison Ford, Linda Davern, Seunghye Park-Lee and Luanna Meyer; Paul H. Brookes Publishing Company, 1989. This manual provides a year-long, step-by-step process for developing a local version of its companion book Community-Referenced Curriculum Guide (see above). The process was field-tested across 12 school districts in 8 states. This manual emphasizes the importance of determining a district's individual strengths and needs, as well as involving both parents and teachers in curriculum development.

Metropolitan Council DD Program
Mears Park Centre
230 East Fifth Street
St. Paul, MN 55101

If you no longer wish to receive this newsletter, please call (612) 291-6364, or write to the DD Program, Metropolitan Council Mears Park Centre, 230 East Fifth Street, St. Paul, MN 55101

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D D INFORMATION EXCHANGE

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A NEW DECADE, THE 1990s: BUILDING INCLUSIVE COMMUNITIES

There are no bells in the school, but that's okay because nobody's going anywhere. Jimmy, Billy and Susie stay (with four other students) with Mrs. Jones all day long in their room at the end of the hall. Pictures of snowmen and red woolen mittens hang on the bulletin board. In the back of the room Bobby rocks back and forth, occasionally banging his head on the wall. Nobody tries to stop him. Susie and Jimmy get out their work sheets and point to the blue, red or green squares as Mrs. Jones instructs. Billy is carefully putting pegs in his pegboard. When he is finished, Mrs. Jones dumps them out for him so he can start again. Jimmy comes back from the bathroom with his shirttail out and his fly unzipped. Nobody reminds him. Susie, Jimmy and Billy like Mrs. Jones. They've been in her class for three years now and next year they will go to the workshop. They wonder who will put on their boots and gloves or who will hug them at the end of each day.

The bell rings and Lisa, Zak and Brian leave homeroom to go to their first-bell class. Zak makes a stop at his locker to get his coat because he's going to his job site at a fast-food restaurant and he has to be there by nine a.m. The beeper on his watch has told him it's eight o'clock now so he needs to hurry to catch the bus on time. Lisa wheels her chair into the computer lab and, while the other kids learn programming, she practices her keyboarding skills. The teacher comes by periodically to check her accuracy and gives her a smile that says she's doing fine.

Brian walks to Mr. Green's class where he's working on counting money and making change. Tomorrow they'll go to the mall to check on how much of this he can really do. After school, he will go with the other seniors to the music room where he will practice for graduation. His parents have already arranged some meetings with the rehab counselor and they've been talking about what kind of work Brian wants to do after school.

*Same kids.
Same community.
Same challenges.*

*Different schools.
Different expectations.
Different lives.*

(Written by Cathy Heizman, Child Advocacy Center, Cincinnati, Ohio.)

Last month this newsletter wrote about "support" as a key concept for this decade. In her article about seven children, Ms. Heizman describes the supports that Zak, Lisa and Brian receive on a regular basis in their school program. These include a variety of adaptations to enable them to participate more independently in their home school and to be with their other classmates. All seven children in the article are of transition age, preparing to leave school and go to work. Bobby, Jimmy, Billy and Susie, however, have participated in early childhood activities while in school. They have not learned the skills necessary to go to work. Indeed, their future is a segregated-activity program for adults.

Activities, notices, services, products, etc. mentioned in this publication are for information purposes only and do not imply endorsement by the Development Disabilities Programs of the Metropolitan Council and the State Planning Agency.

It is *support* that makes the difference for the same seven kids who live in the same community and present the same challenges to learning. But because they go to different schools which have vastly different expectations of them, Zak, Lisa and Brian are going to live extremely different lives.

FAMILY LEADERSHIP CONFERENCE

"The Family Leadership Conference" was convened on Jan. 8-9 in Washington, D.C. by the Office of Special Education and Rehabilitative Services (OSERS). The purposes of the conference were to bring together nationally-recognized family leaders to review goals being developed by OSERS and to give families and OSERS staff an opportunity to discuss how families with special needs and OSERS programs can best reflect state-of-the-art research training and services for children and adults with disabilities and their families.

The family leaders presented the visions they hold for their sons and daughters with disabilities, along with types of research, training and services OSERS should strive to have in place so that their visions could become realities by the year 2000. Participants reviewed OSERS' themes of increasing the potential, participation and productivity of citizens with special needs; presenter was OSERS Assistant Secretary Robert R. Davila. During small group work sessions, participants then made suggestions for specific action steps that would help OSERS implement those themes.

Particular attention was given to how the agencies within OSERS establish funding priorities and how they involve families in the priority-setting and peer-review processes. Those in attendance were in agreement that this meeting presented a rare opportunity to spend concentrated time with the leaders of federal agencies. They felt fortunate to have had the chance to openly discuss with federal leadership many issues that affect their daily lives. They also agreed that during the discussions, families seemed to have much higher levels of expectations for their sons and daughters with special needs than had been evident in previous types of family meetings.

FOR YOUR INFORMATION

Self-Esteem Programs Available

The Mental Health Association of Minnesota (MHAM) has two programs on self-esteem available for rent or purchase. The "Very Important Kid" program is for children ages three to six years and consists of 11 activities that encourage children to believe in themselves, to understand and be able to talk about

feelings and to make choices that enhance self-esteem. This well-rated program contains a leader's guide, teacher's booklet, videotape, audiotape, t-shirt, games, posters and "Feeling Face Stars" stickers. The cost is \$29.95 plus \$1 materials fee per participant. The second program on self-esteem for adults is called "Journey To Your True Self." It consists of a guided-imagery slide show and discussion guide and can be presented in an hour by anyone with a basic knowledge of self esteem. The rental is \$10 for groups of 20 with a \$2 shipping charge. Call Cynthia at MHAM for further information on sales or rentals at (612) 331-6840.

"Aware" Fair

An event to increase the awareness of people about others who have deafness or are hard of hearing will be held on Saturday, March 31 at the Fairview Community Center, 1910 W. County Road B in Roseville from 10 a.m. to 3 p.m. Activities will include demonstrations of the "Hearing Dog Program," hearing screenings, Ukrainian egg painting, "Heimlich Maneuver" demonstrations, storytelling, parent and child activities and the Guthrie Theater's "The Magic of the Guthrie." There will be free food and door prizes and there is no charge for the event.

Imagination Inscapes

"Imagination Inscapes" is the name of an art exhibit featuring thought-provoking works by seven Minnesota artists with serious and persistent mental illness. The exhibit will be open until March 5 at the C. G. Rein Galleries in Brandon Square, 3523 W. 70th St., Edina. The gallery is open Monday, Tuesday, Friday, and Saturday until 6 p.m. and Wednesday and Thursday until 9 p.m.

EMPLOYMENT OPPORTUNITIES

Research Assistant

The Institute for Disabilities Studies (IDS) at the University of Minnesota is seeking student-research assistants for a federally-funded study concerning treatments for individuals with mental retardation. The position will involve visiting group homes in the Twin Cities Area to do data collection and analysis three days a week, up to 20 hours per week. Applicants must be available during daytime-working hours. The study is being directed by D. Travis Thompson, IDS director. For further information call Dr. Daniel Cerutti at (612) 627-4506 or Sara Axtell at 627-4503.

Psychologist

ARC Hennepin County is seeking a licensed psychologist or a licensed consulting psychologist to provide direct counseling services to individuals, families and groups, and to supervise family-support and educational-services for this private, non-profit agency which serves people with developmental disabilities and their families. The position requires a State of Minnesota licensure and knowledge of and experience with developmental disability issues. Salary will be \$30,000 per year with excellent benefits. Send resume to: ARC Hennepin County, 2344 Nicollet Av. S., #370, Minneapolis, MN 55404.

PUBLICATIONS

The Supported Employment Parent Training Technical Assistance Project of the Parent Advocacy Coalition for Educational Rights (PACER) has published a "*Reference Manual for Parent Training About Supported Employment.*" The 82-page manual is an annotated bibliography of journal articles, manuscripts, books and audiovisual materials. It also lists parent-training groups which have developed workshops and resources for informing parents about supported employment. The reference manual will help organizations to develop and implement parent-training programs in their own communities. To order the reference manual, send \$5 to SEPTA/TA, c/o PACER Center, 4826 Chicago Av. S., Minneapolis, MN 55417. For more information, call (612) 827-2966 or if you are in Greater Minnesota, call toll-free 1-800-53PACER.

WORKSHOPS/CONFERENCES

March 8

March 15

The ARCs of Hennepin and Anoka Counties are sponsoring two workshops on estate planning and guardianship. Both will be presented by attorneys, Karen Kane of Kane and Leighninger and Rosemary Strunk of First Trust. "Estate Planning will be held on Thursday, March 8 at Edina Community Center, 5701 Normandale Rd., Edina. The Guardianship/Conservatorship workshop will be held on Thursday, March 15 at ARC of Anoka County, 1100 90th Av. N.E., Blaine. The two workshop will be held 7-9 p.m. on both days. The fee is \$10 for ARC members and \$15 for non-members. Reservations are required and may be made by calling ARC Hennepin at (612) 874-6650.

March 12-13

The Region VII Human Development Services of the

Department of Health and Human Services is sponsoring its "Annual Research and Demonstration Conference" at the Westin Crown Center in Kansas City, MO. The workshop sessions will focus on literacy, interdependent living, coordinated services, strengthening families, permanency planning, reducing dependency, and changing patterns of children. The conference fee is \$20. For further information, contact Westover Consultants Inc., 500 E. Street S.W., Suite 910, Washington, D.C. 20024, Attention: Alice Hays, or call (202) 863-0962.

March 22

Courage Center is sponsoring a regional conference for people with disabilities, employers, educators and service providers. The "Say Yes!" conference will focus on perspectives for educating, training and hiring people with disabilities. The conference will be held at the Minneapolis Marriott Bloomington from 8 a.m. to 5 p.m. The registration fee of \$90 includes lunch, breaks and conference materials. Checks may be mailed to Courage Institute, Courage Center, 3915 Golden Valley Rd., Golden Valley, MN 55422.

March 23-24

"Strategies for Integration" will be the topic for a national conference of support for people with severe behavior problems. The conference will be held at the University of South Florida in Tampa, Florida. The fee is \$35. The conference will provide participant with access to practical "state of the art" treatment techniques especially suited for use in homes, schools and community settings. Robert Horner, Jacki Anderson, Glen Dunlap, Robert Koegel, Wayne Sailor and Edward Carr will be the presenters. For further information, contact: School of Extended Studies, LLL012, University of South Florida, Tampa, FL 33620 or call (813) 974-2695.

March 30

ARC Minnesota is sponsoring a workshop on "The Communicative Intent of Behavior" at the Holiday Inn North in Brooklyn Center from 10 a.m. to 4:30 p.m. The presenters will be Jane Carlson, State University of New York at Stonybrook and Mary Piggott, Institute of Disability Studies at the University of Minnesota. The workshop will cover types of communication, functional analysis as a tool to determine the cause of maladaptive behavior, analyzing intentional communication, teaching functional behaviors equivalent to the target behavior, specific programs to use, and types of functional communication systems. The fee of \$65 includes lunch. Send fee to ARC Minnesota, 3225 Lyndale Av. S., Minneapolis, MN 55408. For further information, call (612) 827-5641.

April 3-6

"Your Place or Mine?" is the third annual symposium on creative living environments. Its purpose is to explore and facilitate the creation of personalized community living alternatives for people with disabilities. Topics at the symposium will be values-based housing development, creative community-support services, creative real estate acquisition techniques and ownership option, the creative use of private-investor capital, and ownership alternatives for consumers, parents, advocates and friends. Speakers include Derrick Dufresne, Bob Laux, Jerry Provencal, Ed Skarnulis and Herb Stevens. The symposium will be held at the Bahia Mar Resort and Yachting Center in Fort Lauderdale, Florida. Fee for the symposium is \$195 and may be mailed to Creative Management Associates, P.O. Box 5488, Portsmouth, New Hampshire 03802. Lodging is \$70 per night and reservations may be made by calling 1-800-327-8154. For more information on the symposium, call Cynthia at CMA at (603) 436-6308.

April 17--Twin Cities

April 19--Rochester

April 23--Fairmont

April 26--Marshall

A series of one-day regional workshops for case managers, service providers, family members, advocates and friends on "Personal Futures Planning" are scheduled in different locations in the state. The workshops will introduce participants to the futures-planning process by providing an overview and some practical application. Each workshop will begin at 9 a.m. and end by 4 p.m. The fee of \$50 includes breaks, lunch and handouts. The workshops will be conducted by Jane Wells of Creative Community Options. Send registration to Creative Community Options, 4209 Oakmeade Lane, White Bear Lake, MN 55110. For further information, call Jane at (612) 426-9263.

April 21

An annual self-advocacy meeting is being planned on "Let's Get Serious About Advocating For Ourselves And Others." The mission is "to learn, to be a part of an inclusive community, to express thoughts and feelings, to discover community service, and to greet and celebrate with new and old friends." The meeting will be held at the Anoka Technical College, 1355 W. Hwy. 10, Anoka. The fee is \$12. The meeting sessions will cover relationships, assertiveness, personal futures planning, personal-goal setting, choices, recreation and leisure, humor, and the importance of looking good. These will

be followed by a dinner and dance. The meeting will begin at noon and may go into the evening. For further information, contact your local ARC.

FIVE TRAINING MODULES DEVELOPED

Five new training modules have been developed by the governments Planning Council on Developmental Disabilities. The course work is designed to provide staff training for direct-service staff in five critical areas:

- * **How to Develop Individualized Plans** (how to consider the strengths, opinions, needs and concerns of the persons served).
- * **How To Use Technology To Increase Independence** (how to utilize technology and tools in contributing to an individual's greater independence and sense of self-esteem).
- * **How To Position People With Severe Disabilities** (the "why" and "how" of therapeutic positioning).
- * **How To Improve Behavior Using Non-Aversive Approaches** (how to recognize causes of challenging behavior and develop effective and positive teaching strategies).
- * **How To Supplement Communication Skills** (become familiar with products and methods to assist people who have difficulty using standard forms of communication).

The modules are designed to be implemented through a "train-the-trainer" format. Individuals interested in becoming a trainer for any of the five modules are encouraged to apply. Trainers will be expected to instruct at least four classes (eight hours each) per year, have a flexible schedule and the ability to travel, have prior teaching experience, preferably with adult learners; and have a background working with people with developmental disabilities.

The training sessions will be conducted from March through June. The first--on "How To Improve Behavior Using Non-Aversive Approaches"--will be held on March 15. For further information and registration materials, contact Naomi Beachy (218) 894-3762 or 1-800-247-6836; or Joanne Forrest (218) 828-5344 or 1-800-247-2574. They are with the Brainerd and Staples Technical Colleges.

INFORMATION EXCHANGE

STATE
SUPPLEMENT
March 1990

Developmental Disabilities Program
300 Centennial Office Bldg.
658 Cedar St.
St. Paul, Minnesota 55155

Minnesota State Planning Agency
Roger Strand, *Editor*
(612) 296-4018

COUNCIL'S 1990 REPORT CALLS FOR SYSTEMWIDE ACCOUNTABILITY: EMPOWERING INDIVIDUALS WITH DISABILITIES TOWARD FULL INCLUSION IN COMMUNITIES

"If people with developmental disabilities are to be included in the community, there is critical need for more collaborative efforts between public and private organizations, government, and education. . . We must all work together." This plea was stated in a recently released publication of the Minnesota Governor's Planning Council on Developmental Disabilities entitled, *1990 Report: The Heart of Community is Inclusion*. The Minnesota report, as required by Congress, will be combined with similar reports submitted by other states and territories to the U.S. Department of Health and Human Services that will be presented to Congress this year.

"We need to work together to enable individuals with even the most severe disabilities to begin to conquer and replace: joblessness with a real job at a real wage; inaccessibility with true access; confusion, anger and resentment with choice; and apathy with activism," said Robert Williams, a self-advocate.

Quoting the Americans with Disabilities Act (1989), the Minnesota 1990 Report stated, "Individuals with disabilities are a discrete and insular minority who have been faced with restrictions and limitations, subjected to a position of political powerlessness in our society, based on characteristics that are beyond the control of such individuals and resulting from stereotypic assumptions not truly indicative of the individual ability of such individuals to participate in, and contribute to, society."

"A true community has no walls," the Council's 1990 Report continued. "To be included in a community requires knowledge and information. These two factors are critical in the lives of individuals with disabilities and their families. Lack of knowledge about supports that promote independence, productivity, and inclusion means, fundamentally, that the dreams of individuals and families are limited."

Eligibility: An Issue of Power

Although there has been significant changes in the objective criteria used to determine eligibility, such as expansion of services to persons with "related conditions" (not just those labeled mentally retarded), such changes have resulted from a growing recognition of rights and expectations.

Issues regarding eligibility requirements for services were studied by the Council, especially as related to persons who might be unserved or underserved. Many individuals can be considered as being "underserved," or "those individuals who are currently receiving services, but whose needs are not being met by those services: (1) those who are living, learning, or working in environments which congregate and segregate them, and who are not actively assisted in being present and participating in the community; and (2) those who are being supported to be merely present in the community, but are not being supported to develop and sustain relationships with typical citizens and to participate in the life of the community."

"Through public testimony at hearings, people who are unserved and underserved are those who receive fewer services than others, e.g.: people with epilepsy, cerebral palsy, autism, and head trauma; people who require personal assistance; people who live in rural areas; and members of specific ethnic groups."

Eligibility requirements often result in the exclusion of individuals with developmental disabilities from services. For those deemed eligible, "this often means 'eligible to wait,'" the authors stated.

A major observation in the report was: "There are many Minnesotans with developmental disabilities, or families, who are not aware of available services, and of services for which they might be eligible. There is no widely disseminated, easily accessible, or comprehensive listing of services, and of alternative approaches to service delivery, available to Minnesotans with developmental disabilities."

Critical issues for the 1990s were discussed in the report: having a home and family life; learning, and

working; making sense out of the world; and being supported to participate in the community. In an analysis of issues and funding, "not much has changed over the last few years. There continues to be a wide gap between what we know to be both possible and desirable for people with developmental disabilities, and the situations in which people currently find themselves. There is a gap between policy and practice."

"We have learned that services are most successful when basic needs are addressed. In responding to these basic needs, our hope for the future and our thoughts about the quality of our lives are often concerned with three basic issues: **HAVING A HOME**, not just a roof over our heads; **LEARNING SKILLS** which are useful to our lives and careers of **WORKING**, not just keeping busy. There is a fourth basic issue which gives vitality and fullness to our lives: **DEVELOPING AND SUSTAINING RELATIONSHIPS** with people who depend on us and upon whom we can depend."

"One of the requirements for bridging the gap is to build a system which is truly accountable to persons with developmental disabilities. Accountability implies power. Accountability to the person implies that the person with a developmental disability has power."

"We need to explore some of the ways in which individuals are empowered--to have control over their own lives, and to hold services and systems which have a great deal to do with their lives accountable for what they do."

Dimensions of Power and Accountability

"Individual and family power has a number of ingredients:

- * **System responsiveness:** A system designed to respond to individuals, to be driven by plans developed to increase the person's integration, independence, and productivity.
- * **The individual's community:** A community of people: family, friends, and advocates which enable the individual and the family to develop a vision of what they want and how to get it.
- * **Support to individuals:** The presence of supports in the individual's life which enable the individual to be present and participate in the community.
- * **Concerted action:** A coalition or network of individuals with disabilities, family members, and allies who support one another in achieving a common vision."

"Accountability must exist in four phases of receiving

support: assessment, planning, providing support, and evaluation."

ASSESSMENT: "The individual, family, and friends (people who know the individual best and intimately) are fundamentally responsible for identifying the individual's strengths, needs, preferences, gifts, and talents. The goal of the assessment process is to assist the individual: to belong to the community (integration); to be responsible for as much of one's life as possible (independence); and to contribute to the life of the community (productivity). The fundamental accountability issues at the point of assessment are: Does the assessment portray an individual with strengths, gifts, and capacities? Are the descriptions of the individual positive and useful? Do the descriptions present the individual as a whole person with a life to lead and a future to build?"

PLANNING: "The plan articulates a vision of the individual's future--hopes and dreams, and what will be required to fulfill them. The plan also articulates the demands and expectation to which others will be expected to respond. A plan belongs to the person, not the system. The fundamental accountability issues at the point of planning are:

Whose plan is it? The person's or the system's?

Does the plan describe the ways and means of shaping the world to support the individual or of how the individual will be shaped to fit the system?

Does the plan describe the kind of life the individual wants to lead or is it a description of life in services?"

PROVIDING SUPPORT: Providing support requires marshalling and applying the resources to fulfill the plan."

"One of the bigger problems with the way we go about providing support is that we look at the world only in terms of services. Life comes to be defined as living, learning, working, and playing in special services."

"Assistance' has a much broader meaning. It implies services, but also involves support, technology, and aid."

"The fundamental accountability issues at the point of providing support are:

- * How closely do the supports provided match the original plan? Are services adapted to the individual, or is individual need compromised to meet the current approaches and capabilities of the service?

- * How is funding allocated: Is funding allocated based

on the requirements of individual plans, or based on service requirements regardless of the specific needs of individuals in those services?

- * Do supports increase the individual's inclusion through presence and participation in the community? Or do services involve meeting performance objectives for the individual in isolation from the community?
- * Do supports involve meeting performance objectives for the agency or for the individual? Whose performance is at issue--the agency's in support of the individual, or the individual's in terms of meeting the agency's objectives?
- * Do supports and services involved in an individual's life work together to make sense? Or do compromises with each agency result in a disjointed life for the individual?"

"We suggest the following steps to promote accountability in fulfilling individual plans:

- * A voucher system: Allocate funds to the individual (directly or indirectly). Charges are made against the individual's account as supports are purchased from agencies or individuals.
- * Performance contracting to improve individual outcomes: Allocate funds based on achieving outcomes for the individual, rather than simply providing a service or support.
- * Enable case managers to achieve plan implementation (reduce caseloads): Set caseload limits at a level which allows case managers to be more actively involved in not only identifying existing programs, but adapting them to meet the individual's needs, and developing new supports."

"EVALUATION:" The fundamental accountability issues at the level of evaluation are:

- * Are desired outcomes achieved by, for, and with the individual?
- * Are the general criteria embedded in standards and regulations relevant to the individual?
- * Are specific criteria based on outcomes specified in an individual plan?"

"We recommend the following steps to enrich accountability in evaluation:

- * Friends and family as monitors: Ensure that there are people who are close to the individual (rather

than paid to be) involved in the regular monitoring and evaluation of plan implementation.

- * A checklist system: Have consumers and families use simple, but powerful, checklists to monitor and evaluate services.
- * An objective third party: Identify an objective third party who can receive completed evaluations from individuals, families, and advocates regarding the quality of assessment, planning, and implementation. Have the third party create regular reports on the system's quality and report findings to state agencies, services, and advocacy organizations."

The report concluded with a call for concerted action in common cause:

"In a world or system based on accountability to the individual, the individual's base of power is himself or herself. Until such a system is achieved, however, concerted action by individuals joined in common cause will be necessary."

Copies of the 1990 Report: *The Heart of Community is Inclusion* may be obtained from: Minnesota Governor's Planning Council on Developmental Disabilities; 300 Centennial Office Building; 658 Cedar Street; St. Paul, Minnesota 55155. Tel. (612) 296-4018 voice; or (612) 296-9962 (TDD).

PUBLICATIONS

Staff Guide to Control of Infectious Disease: For the Special Needs Population in Residential Sites and Day Programs, ARC of the United States, 1989. Developed by the Developmental Disabilities Community Nurses Coalition of Boston, Massachusetts, this guide is designed to heighten awareness of infectious disease information, and to overcome common fears and misinformation which act as barriers in accessing appropriate care. Important preventive measures are provided as well as how to contact public health services in each state. Price: \$4.00 per copy. Contact: ARC of the United States; 2501 Avenue J; Arlington, Texas 76006. Tel. (817) 640-0204.

CONFERENCE

March 22-24

"Work Experience Programs and Dept. of Labor Standards" and "Determining Fair and Equitable Wage Payments" are a two-part conference sponsored by the MN Alliance for Training and Technical Assistance and the MN Dept of Education. It will be held at Ruttger's in Brainerd. For information, call (612) 624-0232.

The State Developmental Disabilities (DD) Program Office has acquired several education, training and resource materials. The following materials may be borrowed from the State Office only, located at the address on the front sheet of the State Supplement section of this newsletter. Tel. (612)296-4018.

LENDING LIBRARY SELECTIONS

Persons with Profound Disabilities: Issues and Practices, F. Brown and D. H. Lehr (Eds.), Paul H. Brookes Publishing Company, 1989. As stated in the Foreword by Doug Guess from the University of Kansas, "(This book) should have a major influence on a variety of persons who are looking for new ideas, better methods, and a humane approach to the education and treatment of students with profound handicapping conditions. I enthusiastically recommend this book to the field!" Part I reviews the legal, research, and ethical issues that have emerged. For example, chapters address issues such as: (a) is a policy of exclusion based upon severity of disability legally defensible? (b) meaningful outcomes and methods of classroom integration; and (c) education as related to complex health care needs. Section II addresses practices in interpersonal interactions, educational curricula (including an ecological model), vocational training, and residential services.

Nonaversive Intervention for Behavior Problems: A Manual for Home and Community, L. H. Meyer and I. M. Evans, Paul H. Brookes Publishing Company, 1989. This guide attempts to apply the principles and practices of learning and behavior theory to daily living at home, work, and in the community. The major theme of this manual is the design of behavioral programs that do not compromise the individual's lifestyle and dignity. "Services and supports to adults (and children as well) must reflect recognition of these individual's rights to self-determination," the authors state. Contents concentrates on approaches to address individualized needs in a variety of formal and informal circumstances. Principles and practices useful in the training of service and support professionals are provided. Blank copies of forms in the manual are provided in the Appendix for duplication and use in individual programs.

Metropolitan Council DD Program
Mears Park Centre
230 East Fifth Street
St. Paul, MN 55101

If you no longer wish to receive this newsletter, please call (612) 291-6364, or write to the DD Program, Metropolitan Council Mears Park Centre, 230 East Fifth Street, St. Paul, MN 55101

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April 1990

A NEW DECADE, THE 1990s: BUILDING INCLUSIVE COMMUNITIES.

by Jeffrey L. Strully

Full Inclusion is Possible

Parents dream their children will have futures filled with rich opportunities to grow and develop; meet people who care about them; have happy, successful and complete lives, be good citizens; and do their best.

My wife and I dream the same for our children, including our 17-year-old daughter.

Our daughter, a junior at Arapahoe High School in Littleton, Colo., acts in school plays, is in a drama class and serves on the yearbook staff. She enjoys American literature and the fundamentals of speech and works part-time at the local hospital.

The typical future for such a teenager would include college, working, living near and with people of her choice, having friends and doing what young adults do. In part, schools can help make this possible.

Another way to see our daughter is as a person labeled as severely or profoundly mentally retarded or multi-handicapped and having many challenging needs. These include learning to use the bathroom, walk,

communicate her needs and feed herself. When our daughter is thought about in these terms, there is another image of what her future is and what the role of schools are.

What is our daughter's future when considered in this way? What are her options? Most people see her living in a group home or a more restrictive environment. They see her in an adult-day program where she would learn skills. She would spend her leisure time with her "peers"--other persons with severe and profound labels. She would be surrounded by volunteers, staff, tutors, special friends and other hired help.

These dreams depend upon how we look at this child. What happens in schools can either lead to the first path of a normal life or a second path of a constrained future. Educators' opinions of children and their values and beliefs help determine a child's future, including one who has been labeled.

Schools are in trouble, according to many recent reports. But most of the attention has been focused on "typical" students. Other learners have been forgotten. It is time to think about all learners and for schools to spell out their expectations for all students, not just some.

Our schools must perceive themselves as "inclusive communities" that actively include all learners. Schools must embrace all students--whether the goal is learning to sit, eat lunch or tackling advanced calculus. Competition must be replaced with cooperation. Special

Activities, notices, services, products, etc. mentioned in this publication are for information purposes only and do not imply endorsement by the Development Disabilities Programs of the Metropolitan Council and the State Planning Agency.

and regular education should be merged so all that remains is education. Schools must be places where valuable resources are used effectively to ensure children an equal opportunity to grow and develop to their fullest capability.

Schools are the place to start to achieve a society that includes all people. Schools are the place where differences should be respected and individual learning styles are seen as an attribute rather than a liability. Special education should become a way to assist learners rather than a place to send those who do not fit. Schools must be inclusive to achieve the "American dream" for all children.

Schools and communities must recognize capacities, talents, gifts and strengths of children regardless of how they are described. People who have been labeled in the past can make important contributions to schools.

Our daughter, for example, is inspiring social change at Arapahoe High School, where she helps 2,000 students and faculty wrestle with difficult issues. She challenges the school to question what education is about, to look at its vulnerability and decide on desirable education. Our daughter and other students are learning to live and work together in a community and to find a place for everyone. She is making Arapahoe High School a little more gentle, compassionate and nice. That's not bad for a student who has been seen in terms of deficiencies and needs.

Schools can become places where all children are included if there is a strong commitment to children. If we have a dream for a desirable future for all children, then we will be able to succeed. Perhaps someday because school children are included, communities may change in the way we live together. That wouldn't be such a bad outcome for schools to achieve. Full inclusion is not just about integrating children with labels into the regular education classroom. This goes beyond school reform to a complete restructuring of the educational system. Schools should be valuable for all students, no matter what challenges they pose.

Full inclusions is about schools that embrace differences; where all children have their needs met; where children learn to live with one another; where basic values of education are important to each child, not just some of the children. Only through full inclusion will our children have the opportunity to have a full and rich life. They deserve nothing less.

The above article was written by Jeffrey L. Strully, executive director, ARC Colorado and printed in the "State Government News" Feb. 1990.

EMPLOYMENT OPPORTUNITY

Family Supports Coordinator

The Human Services Support Network, Inc. is seeking a creative, self-generating person to develop innovative supports with families which include a member (or members) with developmental disabilities. The person will facilitate personal futures planning groups, manage services to families and supervise family support services. This position requires competency as a personal futures planning facilitator, the ability to supervise staff providing support and training services in family homes and community settings, and a willingness to push the human services system to provide that which is needed rather than simply directing people to that which is available. Inquiries should be addressed to: Chantal McManus, HSSN, Inc., 357 Oneida Av., St. Paul, MN 55102.

FOR YOUR INFORMATION

SSA Introduces Toll-free Service

The Social Security Administration (SSA) now offers a nationwide, toll-free service to assist people with Social Security questions. The number is 1-800-2345-SSA. It is open 24 hours a day, 365 days a year. Callers can talk directly to a SSA representative if they call between 7 a.m. and 7 p.m. on work days. At other times, SSA uses automatic equipment that allows callers to leave a message. Calls will be returned.

Walk 'N' Roll

The second annual "Minnesota Walk 'n' Roll" will be held on Saturday, June 30 from noon to 4 p.m. The one-mile trek will begin at Juke Box Saturday Night, 14 N. Fifth St. and continue down Fifth to the Hennepin County Government Center in Minneapolis. The event is a wheelchair and walking rally; T-shirts will be given with a \$5 registration fee. Pledge cards are also available. Following the rally will be a picnic buffet, music, dancing and surprises. For further information, call Sara Meyer at Help Yourself, Inc., (612) 378-0848.

Pilot Parents Program

A peer support program called Pilot Parents is available for parents of children with disabilities. The program is designed to match up parents of children with similar disabilities in order to share support and advice. For example, parents with experience in bringing children

with disabilities through the educational system and the processes for developing relationships, employment and community involvement are matched up with parents new to these challenges. To date, about 40 matches have been made, all with positive results. Lynn Frigaard is the statewide coordinator and services in the Duluth area. She can be reached at (218) 726-4745. Jacki Stalley, ARC St. Paul, serves the Twin Cities Area and can be reached at (612) 297-6231.

CONFERENCES/WORKSHOPS

April 17--Twin Cities

April 19--Rochester

April 23--Fairmont

April 26--Marshall

A series of one-day regional workshops for case managers, service providers, family members, advocates and firends on "Personal Futures Planning" are scheduled in different locations in the state. The workshops will introduce participants to the futures planning process by providing an overview and some practical application. Each workshop will begin at 9 a.m. and end by 4 p.m. The fee of \$50 includes breaks, lunch and handouts. The workshops will be conducted by Jane Wells. Each workshop is limited to 40 participants. Contact: Jane Wells, Creative Community Options; 4209 Oakmede Lane; White Bear Lake, MN 55110. Tel. (612) 426-9263.

April 24 and May 21

Planned Parenthood of Minnesota is sponsoring a workshop titled "*AIDS and Developmental Disabilities: Policy Approaches for the '90s.*" Earl Pike, AIDS guidelines specialist for the Chemical Dependency Division for the Department of Human Services, will be the presenter. The workshop is targeted to administrators, directors and mid-level managers. On April 24 the workshop will go from 9 a.m. to 4:30 p.m. and on May 21 from 9 a.m. to 1 p.m. It will be held at the Earle Brown Continuing Education Center, 1890 Buford Av., St. Paul. The registration fee is \$40 and payable to Planned Parenthood of Minnesota, 1965 Ford Parkway, St. Paul, MN 55116. For further information, call Lisa Wilcox at (612) 698-2401.

April 26

"*An Overview of Developmental Disabilities*" is a workshop designed to meet state licensing requirement for staff training. It is of value to parents, case managers, educators and other professionals and paraprofessionals in the developmental disabilities field.

It covers the historical perspective on developmental disabilities; reviews the definitions and causes of mental retardation, cerebral palsy, epilepsy and autism; the principle of partial participation, normalization, least restrictive environment; and the criterion of ultimate functioning. The workshop will be held at the Kelly Inn, I-94 and Marion St. St. Paul from 1 to 4 p.m. The presenter will be Eleanor Field. The fee is \$20 and Payable to Thomas Allen, Inc., 1555 Livingston Av. W., St. Paul, MN 55118. For further information or a brochure, call Julie Hanson at (612) 450-1802.

April 26

The Minnesota Chapter of the American Association on Mental Retardation (AAMR) is sponsoring a one-day workshop titled "*Aging and Death, Sexuality and Keeping Informed, Dealing with Three Difficult Topics for Modern Services to People with Developmental Disabilities.*" It will be held from 9 a.m. to 4:30 p.m. at McGuire's Inn, 1201 W. County Road E., Arden Hills. Speakers will be author and teacher Eunice McClurg, services developer Liz Curren and sexuality training systems developers Elaine Jurkowski, Laurienne Ring and Aileen Urquhart. The fee is \$20 for members, \$15 for students or relatives of people with developmental disabilities and \$30 for non-members. The fee includes lunch. Mail fees payable to AAMR Minnesota Chapter to Marianne Reich, ARC Suburban, 14451 County Rd. 11, Burnsville, MN 55337. For further information call Marianne at (612) 431-3700.

May 3-5

The ninth annual conference on the "*Training and Employment of Paraprofessionals in Education, Rehabilitation and Residential Services for Children and Adults of Disabilities*" will be held at the Sabal Park Holiday Inn in Tampa, Florida. Topics to be covered include expanding roles of paraprofessionals in the transition of teenagers and young adults from school to work, changing duties of paraprofessionals in early intervention and pre-school programs, the role of paraprofessionals in facilitating the unification and integration of general and special education programs, curriculum and training materials to prepare them for these new duties, and strategies for integrating paraprofessionals into different programs and settings. For more information, contact the National Resource Center for Paraprofessionals, CASE/CUNY Graduate Center, Room 620N, 25 W. 43rd St., New York, NY 10036 or (212) 642-2948.

May 5

"*Celebrate Siblings*" is a workshop for families of children with special needs. This is an opportunity to focus attention on the needs of other members of the special

needs family: the sibling(s) of a person with developmental disabilities. There will be a discussion group and interactive games. The workshop will be held from 9 a.m. to noon at the Eisenhower Community Center, second floor library, 1001 Hwy 7, Hopkins, MN. The fee is \$5 per family payable to West Hennepin Community Center. Child care is available for \$2 per child. Call the center at (612) 933-9105 to register.

May 19-20

The Parent Advocacy Coalition for Education Rights (PACER) will hold its first statewide parent conference titled "*We the Parents*" at the Bloomington Marriott Hotel. The event will begin at 10 a.m. on Saturday and last until 1 p.m. on Sunday. The registration fee is \$25 per parent and will cover lunches both days and a reception and dinner Saturday evening, conference materials and hotel accommodations for those in Greater Minnesota. Patte Smith, executive director of the National Network of Parent Centers, is the keynote speaker. Other national and state speakers will address various issues on parenting children with special needs, including advocacy, early childhood, transition, emotional and behavioral disorders, guardianship, estate planning and many other topics. For further information and a registration form, call (612) 827-2966 or toll-free 1-800-53PACER.

May 24-27

The sixth annual conference of the International Rett Syndrome Association (IRSA) will be held at the Crystal Gateway Marriott in Washington, D.C. The conference will feature information on the medical and scientific aspects of the disorder, educational and management techniques and understanding family issues. The program will also feature professor Andreas Rett of Vienna, Austria, who discovered the syndrome over 25 years ago. For further information and registrations forms, contact IRSA, 8511 Rose Marie Dr., St. Washington, MD 20744 or (301) 24-7031. Fax: (301) 248-9049.

May 27-30

The Association for the Care of Children's Health (ACCH) is holding its 25th annual conference, "*Shaping the Future of Children's Health Care*," at The Grand Hyatt in Washington, D.C. The goals are to provide a multi-disciplinary forum for exchange of practice, research, programming, and policy information; outline an agenda for enduring the quality of children's health care in the next decade; and to address "best practice" in psychosocial, developmentally supportive, family-centered pediatric health care in all possible settings. The fee is \$150 for members and \$280 for non-members. There are 117 workshop sessions and numerous general session

speakers. For a conference booklet, contact ACCH Conference Registration, 3615 Wisconsin Av. N.W., Washington D.C. 20016-3007.

July 13-14

The Association for Persons in Supported Employment (ASPE) is putting on its first annual conference at the Radisson Hotel Denver in Denver, Colorado. The theme is "*Supported Employment: Here to Stay*." Topics will include program management, Social Security work incentives, social integration, personal futures planning, empowerment, rural supports systems change program conversion, funding including long-term funding, legislative issues, quality assurance, relationships with business, and supported employment for persons residing in institutions and those with mental illness. For further information on the conference and registration forms, contact APSE, 5001 W. Broad St. Suite 34, Richmond, VA 23230 or (804) 282-3655.

May 14-16

"*SENSATIONS: Stimulation, Innovation, Visualization, Motivation, Destination*" is the theme of the 1990 annual conference of the Association of Residential Resources in Minnesota. The conference will be held at the Radisson South Hotel, Bloomington, Minn. For further information, contact: ARRM, 26 East Exchange Street, St. Paul, MN 55101. Tel. (612) 291-1086, or (800) 551-2211, toll-free.

May 23-25

A multi-organizational conference, "*Shaping Alternative Futures: Strategies for Effective Integration*," will be held at the Fantasyland Hotel in Edmonton, Alberta, Canada. The conference will explore strategies to facilitate inclusion of persons with challenging needs in the mainstream of educational, vocational, recreational, and community living options. Contact: Shaping Alternative Futures Conference, Alberta Education Response Centre, 6240--113 St., Edmonton, Alberta, Canada T6H 3L2.

May 27-31

The American Association on Mental Retardation will hold its 114th annual meeting and exhibit show at the Atlanta Hilton & Towers, Atlanta, Georgia. The theme is "*A Better Way of Life: Policy, Research, and Practice*." For more information and registration, contact: AAMR, T. Myers, U.S. Postal Service, Customer Services, Room 2004, 2 Massachusetts Av. NE, Washington, D.C. 20066-9605.

INFORMATION EXCHANGE

STATE
SUPPLEMENT
April 1990

Developmental Disabilities Program
300 Centennial Office Bldg.
658 Cedar St.
St. Paul, Minnesota 55155

Minnesota State Planning Agency
Roger Strand, *Editor*
(612) 296-4018

SUPPORT, NOT SUPPLANT THE FAMILY: AN END OF DECADE REPORT ON FAMILY SUPPORT SERVICES

As cited in a recent study by the Human Services Research Institute, Cambridge, Massachusetts, "One of the earliest critics of the emerging pattern of 'community-based' services was Edward Skarnulis in 1979 (now at the University of Minnesota), who called for policy makers and providers to stop 'supplanting' the family and start supporting it. The wisdom of this observation . . . has taken a decade to influence the national trends in the field." This comment is contained in a recently released study of all 50 states, entitled, *Family Support Services in the United States: An End of Decade Status Report* (February 1990), by Valerie J. Bradley, Project Director, James A. Knoll, Susan Covert, Ruth Osuch, Susan O'Connor, John Agosta, and Bruce Blaney. This study was designed as one aspect of a larger effort to provide states with technical assistance related to the development of a systematic approach to family supports.

Some of the highlights of the results in this study revealed that:

- * Forty-five states have developed programs with a specific focus on supporting families that are raising a child with a developmental disability. These programs provided some service to at least 129,777 families during the last state fiscal year.
- * The average allocation among these states is \$3,826,623 with a national total of \$172,198,035. When this is compared to the national budget of \$11,716,825,830 for services for people with mental retardation and developmental disabilities (Braddock, et al., 1990), this amounts to a commitment of approximately 1.5% of this amount to support approximately 129,777 families.

While this study documented that there is a wide variety among the states in their development of family support

services, it is most helpful in defining the terms we use. In a review of professional literature, the authors found that:

"There are a unifying core of principles related to support of families of people with disabilities. Central to these principles is the knowledge that every family is different; just as no two persons with disabilities are exactly alike. This means that the supports a family might need can differ from those needed by other families. This has led many to conclude that the 'support' in family support should be defined by the family. As such, a family support program must be prepared to provide *whatever it takes to maintain and enhance the family's capability to provide care at home.*"

"Family support must be construed as a flexible and varied network of supports that can accommodate individual family concerns. Moreover, to be most effective family supports must be administered in ways that enable and empower families and persons with disabilities to maintain or regain control over their own lives and the lives of their family. It seems central to achieving this goal that the supports offered to families must be administered so that they are family centered, culturally sensitive, community-centered, and well-coordinated:

- * Family centered approaches includes three basic premises:
 1. Services should enable families to make informed decisions. Service models must be founded on the presumption that families are potentially capable and willing to make responsible decisions; families want the best for their children.
 2. Services should be responsive to the needs of the entire family. Within a family systems framework, the family is viewed as an interacting, reacting system that is delicately balanced and struggles to maintain that balance. A change or problem in one aspect of the system affects the entire system. Thus, family support practices cannot be directed solely at the needs of the child. Rather, supports should be

available to other family caregivers, with the intent of enhancing the family's overall capacity to provide care.

3. Services should be flexible enough to accommodate unique needs. Needs change over time. This means that responsive programs must permit a wide array of supports (i.e. multiple support options) and must encourage each family to select those that are most appropriate."

* "Culturally sensitive approaches. No single approach to supporting families is likely to work with all families. Differences in family type, culture, income, and geographic location call for diversity in the approaches undertaken."

* "Community-centered approaches. Present practice increasingly relies on alternatives available through generic community services, the private sector, or within informal helping networks to complement publicly funded specialized services. Such supports are believed to be most effective and least costly when their source is closest to the family, both geographically and personally. Many supports can and should be available through informal means or from the private sector (e.g. extended family, friends, neighbors, employer benefits, and private health insurers). In fact, by focusing on governmental solutions exclusively, existing helping networks may inadvertently be displaced or other potential sources of support may never be utilized."

* "Comprehensive and well coordinated approaches. Built into any approach to supporting families must be ways to utilize what already exists in the community. Numerous programs presently exist. The challenge facing service practitioners is to weave these potential sources of support together in a manner that assures: 1) the child with disabilities receives needed habilitative or health related services; 2) family members receive the supports they need to enhance their capacity to provide care and to function as a family; and 3) potential community centered helping networks, outside the public domain, are utilized to the full extent feasible."

The following taxonomy was used to record the variety of family support activities in the 50 states studied:

SERVICES

CORE SERVICES:

RESPIRE & CHILD CARE

Respite

Child Care

Sitter Services

IN-HOME ASSISTANCE

Homemaker
Attendant Care
Home Health Care
Chores

ENVIRONMENTAL ADAPTATIONS

Adaptive Equipment
Home Modification

RECREATION

Recreation
Camp

SUPPORTIVE

Family Counseling
Family Support Groups

TRAINING

Parent Training

SYSTEMIC ASSISTANCE

Information/Referral
Advocacy

EXTRAORDINARY/ORDINARY NEEDS

Transportation
Vehicle Modification
Special Diet
Special Clothing
Utilities
Health Insurance
Home Repairs
Rent Assistance

TRADITIONAL DEVELOPMENTAL SERVICES

Behavior Management
Individual Counseling
Evaluation/Assessment
Medical/Dental
Nursing
Occupational/Physical Therapy
Skill Training
Speech Therapy

CASEMANAGEMENT/SERVICE COORDINATION

FINANCIAL ASSISTANCE

Discretionary cash subsidy
Vouchers
Line of Credit
Allowances
Reimbursement

"The last decade has seen most states make the decision to get out of the business of running large congregate care institutions. Our reading of the direction in family supports leads us to conclude that within the next decade each state will confront another fundamental decision about its policy direction. In its most concise form, the question confronting policy makers is 'Will we continue with business as usual, placing our primary emphasis on funding programs and facilities and providing minimal support to families and adults with disabilities who live outside our facilities, or will we shift to a truly individually driven system in which we fund the unique constellation of services and supports that each person needs?'"

Copies of the report may be obtained from: Human Services Research Institute; 2336 Massachusetts Avenue; Cambridge, MA 02140. Tel. (617) 876-0426.

ASSISTIVE TECHNOLOGY INFORMATION NETWORK ESTABLISHED

(800) 331-3027

A new toll-free number for people living in Minnesota and Iowa is now available for the purpose of providing up-to-date information about assistive technology:

1 (800) 331-356-1514 (Voice and TDD)

Information Services are available on weekdays, 8:00 a.m. to 5:00 p.m.

This Information Network is a cooperative effort between the Minnesota S.T.A.R. Project of the Minnesota Governor's Advisory Council on Technology for People with Disabilities and the Assistive Technology Information Network of the Iowa University Affiliated Program.

"Assistive technology" is any piece of equipment that a person with a disability can use as an aid to increase independence; a range of items from easy-grip pens to power-driven wheelchairs, or from computerized communication boards to specially designed microswitches. The following information will be made available:

What assistive devices are available to meet your needs?

Who produces these devices, whether it is an individual or a company?

How do the costs of different devices compare?

How can you order the device you need?

For more information, and for a free newsletter subscription, contact: Assistive Technology Information Network; Iowa University Affiliated Program; University Hospital School; The University of Iowa; Iowa City, Iowa 52242. Telephone: (319) 356-1514.

ARC-US FUNDED TO IMPLEMENT HIV PREVENTION PROGRAM

The Association for Retarded Citizens of the United States has been awarded federal funding from the Public Health Service of the Centers for Disease Control to implement a three-year national education program to prevent the spread of Human Immunodeficiency Virus (including AIDS) among adults with developmental disabilities. Seven national organizations will assist in

the development of educational materials and a nationwide training program. These organizations include: the American Association of University Affiliated Programs for Persons with Developmental Disabilities, American Association on Mental Retardation, National Easter Seal Society, Volunteers of America, National Association of Protection and Advocacy Systems, United Cerebral Palsy Associations and the Association for the Advancement of Health Education. For information: ARC USA 2501 Avenue J; Arlington, Texas 76006. Tel. (817) 640-0204.

PUBLICATIONS/RESOURCES

Critical Issues in the Lives of People with Severe Disabilities, L. Meyer, C. Peck, and L. Brown (Eds.), Paul H. Brookes Publishing Company, 1990. "The intention of this volume (over 700 pages) was to create a comprehensive resource that would both chronicle the 'state of the art' and lay out the challenges now confronting us if we are to achieve what Frank Laski aptly refers to, in his chapter, as the 'second revolution' for people with severe disabilities," said Luanna Meyer, co-editor. Each section opens with a series of values statements, written by experts and advocates, to serve as guides to decisions about policies and practices. Some of the topics covered include: testing and diagnosis, recreation and leisure, community living, supported employment, social relationships, integrated education, personnel preparation, early childhood services, medical treatment, extended school year, and nonaversive behavioral intervention. For more information, contact: Paul H. Brookes Publishing Co., P.O. Box 10624, Baltimore, MD 21285 or (800) 638-3775.

1990 Supported Employment Resource Guide, National Association of Rehabilitation Facilities, 1990. This guide lists technical assistance, training, research, and other related resources available on supported employment. The guide includes audiovisual resources and bibliographic information developed during the past five years. For information, contact: Supported Employment Demonstration Project; National Association of Rehabilitation Facilities; P.O. Box 17675; Washington, DC 20041-0675. Tel. (703) 648-9300.

Quality Health Care: A Guide for Health Professionals, Institute on Community Integration, University of Minnesota (1990). A companion to *Quality Health Care*, which was designed for parents and other caregivers, this new edition offers health care providers guidelines for serving persons with disabilities. Chapters include: general child and adolescent health care, adult health care, nutrition, reproductive health care and sexuality, dental care, infectious disease, and chronic health conditions. Available through: Institute on Community Integration; University of Minnesota; Pattee Hall; 150 Pillsbury Drive, S.E.; Minneapolis, MN 55455.

The State Developmental Disabilities (DD) Program Office has acquired several education, training and resource materials. The following materials may be borrowed from the State Office only, located at the address on the front sheet of the State Supplement section of this newsletter. Tel. (612)296-4018.

LENDING LIBRARY SELECTIONS

Quality Assurance for Individuals with Developmental Disabilities: It's Everybody's Business, V. J. Bradley, and H. A. Bersani (Eds.), Paul H. Brookes Publishing Company, 1990. As the title of this book implies, quality assurance is everybody's business. Many contributing authors (including John O'Brien, Lyle Wray, Robert Gettings, Gerald Provencal, and James Knoll) provide a framework for understanding quality assurance within the context of a decentralized, integrated service system. The editors forewarn, "State and federal government officials cannot continue to be the sole authorities for ensuring quality. They have to share the responsibility of establishing a unifying vision to guide the delivery of services and designing funding arrangements that support rather than constrain the realization of integrated community services. Without this vision, the current health pluralism that characterizes the system will begin to deteriorate into disorganization and incoherence." Content includes: various viewpoints (such as self-advocates and family members); issues (e.g. governmental, management, advocacy, accreditation, and research); and innovative examples of local monitoring programs as well as quality assurance systems. Provencal points to the consumer as the key to quality assurance, "Experience has shown that when consumers are given responsible and active parts to play in the delivery system, the health of the

community network improves noticeably. . . . The customer is far and away the best barometer for determining whether or not services are quality ones."

Transition from School to Work: New Challenges for Youth with Severe Disabilities, P. Wehman, S. Moon, J.M. Everson, W. Wood, and J.M. Barcus, Paul H. Brookes Publishing Company, 1988. This book provides its widely intended audience with a guide for planning and implementing successful transition programs for adolescents with disabilities. It is a comprehensive look at the transition movement, with special attention devoted to service provision for students with severe disabilities. The authors emphasize that when professionals and parents work closely together on a single goal, significant outcomes can accrue--especially sustained employment. Three phases are covered: 1) preparing for transition in the school years; 2) initiating careful transition program planning, and 3) developing employment options and achieving successful placements. Federal and state programs are described, and sample forms are provided that can be used to facilitate individual plans. The authors conclude, "What is clear is that for a program to be successful, there must be a reliance on individualized program planning, service delivery, and interagency coordination. These elements are the backbone of any effective transition programming."

Metropolitan Council DD Program
Mears Park Centre
230 East Fifth Street
St. Paul, MN 55101

If you no longer wish to receive this newsletter, please call (612) 291-6364, or write to the DD Program, Metropolitan Council Mears Park Centre, 230 East Fifth Street, St. Paul, MN 55101

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A NEW DECADE, THE 1990s: BUILDING INCLUSIVE COMMUNITIES

Inclusiveness at Work: What We Are Learning

Supported employment focuses upon "competitive work in an integrated work setting for individuals who, because of their handicaps, need ongoing support services to perform that work," (Federal Register, August 14, 1987, p. 30546). Supported employment also provides opportunities for people with disabilities to interact with nonhandicapped employees. In the eight or ten years we have been involved in supported employment, we have learned that people with developmental disabilities can and do learn their jobs with support, but we know very little about social interactions between people with and without disabilities. Various authors suggest that typical social interactions include sharing of information, teasing and joking with others and asking questions. Also co-workers can be resources for support for supported workers.

In Illinois, Frank R. Rusch, John R. Johnson and Carolyn Hughes want to know more about the social interactions of supported workers with their nonhandicapped co-workers. They studied 264 supported employees in relation to level of their disability versus the type of their placement (i.e. individual, clustered, crew). More specifically their study sought to describe the type and level of co-worker involvement being reported by employment specialist who place their supported employees individually, in groups (e.g.,

clusters), or in mobile work crews. Additionally, the relationship between the level of disability and type of placement was investigated.

The supported employees in the study were selected because they had mental retardation (mild, moderate, or severe/profound) as a primary disability, there was complete co-worker data available during a specified time block, and all were in one of three Illinois government funded, supported employment programs.

Participating rehabilitation agencies completed each month a Co-worker Involvement Reporting Form provided by the researchers. Employment specialists, after being trained in collecting the data, were primarily responsible for completing the forms and returning them to the researchers. The Co-worker Involvement Reporting Form consisted of two sections. One section assessed employment specialist hours provided to the supported employee. The second section consisted of six items involved evaluating the occurrence or nonoccurrence of types of co-worker involvement provided to the supported employee (training, associating, befriending, advocating, collecting data, evaluating).

The results showed some interesting findings. First of all, associating (interacting socially at work) with nondisabled co-workers was reported more often than any other type of co-worker involvement. Conversely, 0-35% of supported employees appeared to be befriended (interacting socially outside of work) by nondisabled co-workers. Also supported employees working in

Activities, notices, services, products, etc. mentioned in this publication are for information purposes only and do not imply endorsement by the Developmental Disabilities Programs of the Metropolitan Council and the State Planning Agency.

individual placements represent the largest proportion of individuals experiencing co-worker involvement. Conversely, a low percentage of persons working in mobile crews had experience co-worker involvement. Level of disability was a factor relating to frequency of co-worker involvement and it appears that individuals experiencing the most severe disabilities tended to have fewer opportunities for co-worker involvement in the form of befriending, advocating (encouraging, backing rights, supporting) and data collection than other supported employees.

Regardless of disability, this study indicates that co-workers associated with the majority of supported employees working in individual and clustered supported employment situations. However, associations decreased significantly when workers were in mobile crews. Fewer than half of all persons, regardless of disability or type of supported employment placement, had experienced befriending by nondisabled co-workers. Only one of 23 people in mobile crews experienced befriending.

The number of people who experienced advocating seemed to be affected by both disability and placement. The probability of nondisabled co-workers acting as advocates seemed to decrease as the severity of primary disability increased. In addition, as the type of supported employment placement became more group oriented, the probability of co-workers acting as advocates also decreased.

The results also showed that individuals working in individual placements had more opportunities to receive training from nondisabled co-workers than persons working in either clustered or mobile crew situations. Also those in individualized placements tended to receive more evaluation for co-workers than their peers working in the other two types of employment situations.

This study supports growing reports that suggest that supported employees are involved with nonhandicapped co-workers. Indeed, naturally occurring co-worker support has been found to be typical of work environments. It appeared that co-workers associate with supported employees during the work day and that these same co-workers assume evaluation and training responsibilities. Additionally, co-workers appear to associate, evaluate, and train the supported employee more often when the employee has mild mental retardation as opposed to severe mental retardation.

The findings also suggest that the type of placement results in significantly different levels of co-worker involvement. We found that supported employees who were employed in mobile work crews were much less involved with co-workers. Supported employees who were individually placed or who worked in clustered placements were more involved with co-workers. Not

surprising, typically, mobile work crews consist of eight or fewer supported employees performing subcontract work. These employees are often transported by a company van to different settings to perform janitorial or maintenance jobs, and are jobs usually performed when the contracting agency is no longer open to the public. The authors suggest that because a lack of employment integration is typical of mobile work crews, it may be that the limited opportunity for co-worker support makes these placements inappropriate for supported employment if our defining feature for it is employment integration. Without the opportunity to interact with nondisabled co-workers in the workplace, it is unlikely that employees with disabilities can participate as equal members of the work force.

This study also suggests that although nondisabled co-workers associate with supported employees, they rarely invite these employees to participate in religious or recreational activities, away from the workplace. Clearly, the results of this study suggest that if supported employees are not making friends, then supported employment professionals need to develop and implement systematic and natural means of facilitating interactions between nondisabled co-workers and supported employees.

The results of befriending may also have some important implication for job tenure and job separation. Typically, employment offers employees opportunities to develop social relationships and engage in social activities. The authors think, although it was not a part of this study, that there may be a relationship between the amount of befriending that occurs on a job and job separation.

In summary, the findings of this study point to the possibility that nondisable co-workers do assume significant relationships with supported employees, unless the supported employees are members of mobile work crews. The findings also indicate that the type of supported employment placement is the single most powerful measure of the number of persons for whom co-worker involvement had occurred.

A summary from: *Analysis of Co-Worker Involvement in Relation to Level of Disability versus Placement Approach among Supported Employees*, Frank R. Rusch, John R. Johnson, Carol Hughes, The Journal of The Association for Persons with Severe Handicaps, Vol. 15, Number 1, Spring 1990.

FOR YOUR INFORMATION

Advocacy at Work

Advocacy Plus Action, Inc. is a non-profit organization in

St. Cloud, Minn. which benefits children and adults with disabilities on a local, regional, state and national levels. Program service includes the following: accessibility, advocacy, attendant care, awareness seminars, case management, chemical dependency, employment, housing recreation, support services and transportation. The mission is to further the well-being and quality of life for children and adults with disabilities by promoting the maximum independence, personal responsibility, self-esteem and dignity of people who are physically and mentally challenged; providing, pioneering and promoting vital and caring programs and services at appropriate local, state, regional, national and international levels; sharing its knowledge and experience with others who work with disabled persons; and promoting public awareness of the abilities and needs of individuals who have disabilities to facilitate their full and equal participation in society. For further information, contact Kathleen T. Wingen at Advocacy Plus Action, P.O. Box 5001, St. Cloud, MN 56302 or (612) 259-4003.

Training Program on Epilepsy Available

The Epilepsy Research Center at the University of Minnesota has recently produced a training package about epilepsy titled, "Epilepsy: A Positive I- D." It is designed for health educators, epilepsy educators and other professionals who teach people about epilepsy. It will help people recognize common seizures, administer appropriate first aid and identify epilepsy medications. A twenty-two minute videotape illustrates the two types of seizures most frequently encountered, the generalized tonic clonic (grand mal) and the complex partial. It emphasizes that complex partial seizures can be easily be mistaken for drunken behavior or drug abuse, and outlines ways to tell the difference. An instructor's manual is included with the videotape. The package is available for rent or for purchase. The rental price is \$25 and the purchase price is \$100. For further information or to order, contact Epilepsy Education, University of Minnesota, 2701 University Av. S.E., #106, Minneapolis, MN 55414 or call (612) 331-4477.

Child Sitter Program

The Minneapolis Council of Camp Fire in collaboration with ARC of Hennepin and Anoka counties has recently implemented a program called "Special Sitters" which is a program to train young people to care for children who have disabilities. The program consists of 15 hours of activities designed to prepare teenagers to child sit for most children who have developmental disabilities. Through the training, teenagers learn how to listen to parents and to gather the information they need to know about each child's care requirements. Sitters discover

ways to play with children of varying ages and abilities in a manner that is responsive to the individual child. They learn to follow special parent-directed behavior programs, to anticipate and respond to good behavior and simple ways to confront undesirable behaviors. Sitters experience alternative communication systems and learn the importance of responding both verbally and non-verbally to children. They also learn about feelings, medications and adaptive equipment. In addition to the 15 hours of sitter training, the sitters receive six hours of Red Cross first aid training. Trained sitters are available in most communities in Hennepin County. Parents who are interested in finding out more about the program, would like to sponsor their own sitter to take the training, or would like the names of trained sitters in their area may call the Minneapolis Council of Camp Fire at (612) 925-0205. Agencies in communities outside of Hennepin County who would like to consider starting a sitter training project through their agency may also call the Camp Fire office at the same number.

Summer Recreation Opportunities

Camp Friendship in Annandale, Minn. will be offering a new option in summer camping this year by offering integrated camping services. This option will serve as a bridge to facilitate entrance of children with developmental disabilities into regular day and residential camps. Camp Friendship will provide support through training of regular camp staff and acting as liaison between families with children with special needs and the regular camps. Another summer option for people with developmental disabilities is the VENTURES travel service also operated by Camp Friendship. It offers a variety of small group vacations for teenagers and adults. The vacations feature off-site and outstate experiences to places such as Memphis, Tenn. and Niagara Falls. Other trips explore Minnesota with trips to Duluth, Mille Lacs or the Voyager National Forest in a houseboat. Accommodations include tent camping or resorting. For further information about either of these programs, contact Camp Friendship, Route #, Box 162, Annandale, MN 55302 or call (612) 274-8376.

PUBLICATIONS AND VIDEOS

Dental Care

"Preventing Dental Diseases in Children with Disabilities" is a packet of information covering at-home oral care; positions for cleaning teeth; brushing, flossing and rinsing; professional dental care; common dental problems; growth and development; checklist for selecting a dental office; and tips for planning successful dental visits. For a free copy of this kit, please contact:

Ann Balson, ARC-US, 2501 Av. J, Arlington, TX 76006
or call (817) 640-0204.

Cultural Diversity Information

"A Bibliography of Selected Resources on Cultural Diversity for Parent and Professionals Working with Young Children Who Have, or Are at Risk for, Disabilities" is a 68-page annotated bibliography listing books, journal articles and newsletters plus selected organizations across the country with regard to a wide range of disabilities. While the focus is on early childhood resources, the bibliography is general enough to be useful for all age groups. The intent of the publications is to facilitate networking and collaboration in working with culturally diverse populations. The materials are divided into two categories: 1) general information on cultural diversity, and 2) resource information on selected cultural/ethnic populations. To order a copy, send \$6 per copy to PACER Center, 4826 Chicago Av. S., Minneapolis, MN 55417-1055.

Recreational Adaptations

Ablenet has recently published two new books which should promote integration for people of a variety of ages by using a variety of adaptations. *Turn Style* is a booklet which describes 11 different projects you can create with spin-and-paint hobby sets. It includes complete instruction and illustrations of the activities plus suggestions on where to purchase materials to make a wide variety of fun creations. The cost of the book is \$9. *Fun for Everyone* is a comprehensive book that evaluates many toys and games presently available in most stores. It suggests simple ways to adapt the games and rules of play so people with disabilities can participate with their peers to enjoy their leisure time together. The cost of this publication is \$20. Either or both publications can be ordered by sending a check to Ablenet, 1081 Tenth Av. S.E., Minneapolis, MN 55414. For further information, call (612) 379-0956 or toll free (800) 322-0956.

WORKSHOPS/CONFERENCES

May 5

"A Potpourri of Ideas" is the Educator Network Spring Conference for teachers of students with hearing impairments, audiologists, program coordinators, speech and language clinicians, special education directors, educational interpreters and parents and friends. Robert Geesey of the Minnesota Council for the Hearing Impaired will provide the keynote on "Deaf Children in the Mainstream: Expectations Versus Realities." Following this there will be workshops on socialization, deaf culture, chemical dependency, program planning,

student support, consultation skills, parent interaction and communications systems. The conference will be held at the Park Inn International, 250 Canal Park Dr., Duluth, MN. The fee is \$15 for member and \$25 for non-members. Rooms are \$44. To register, send checks to Minnesota Foundation for Better Hearing and Speech, Community Services Building, 166 E. Fourth St., Suite 320, St. Paul, MN 55101. For further information call Valerie Williams at MFBHS at (612) 223-5130/VTDD in the Metro Area or (800) 228-2506/VTDD in the Outstate Area.

May 9, Minneapolis

May 11, Duluth

"Maximizing Staff Consistency in Program Implementation" is a workshop of increasing program effectiveness for individuals with special needs. The workshop focus is on a review of research, case study applications, describing strategies that have been developed and implemented, small group activities to develop a system to maximize staff consistency in program implementation, and problem solving. The workshop is sponsored by the Institute for Applied Behavior Analysis and Gary W. LaVign, Ph.D. clinical director of the institute, will be the presenter. The cost of the workshop is \$85 and includes materials. The workshop in Minneapolis will be at the Ramada Inn, 4460 W. 78th St. Bloomington and in Duluth at the Fitger's Inn, 600 E. Superior St. Registrations may be sent to the Institute for Applied Behavior Analysis, 6169 St. Andrews Rd., Suite 123, Columbia, SC 29212. For further information, call (803) 731-8597.

May 12

"Exploring Education Funding--Issues into the 1990s" is sponsored by ARC Suburban and the ARC Minnesota Education Committee to provide information to parents about regular and special education funding issues, new funding programs and the future. Panel members from the Minnesota Legislature, the Department of Education, Regular and Special Education Administration, unions and advocacy organizations will discuss state and local funding issues, program issues (integration and quality of education), goals and mission statements for each entity and third party reimbursement. Small group discussions will follow to develop a vision of the future of education and how parents might get there. The workshop will begin at 9 a.m. and end at 3 p.m. and will be held at the United Way Multi-Service Center, 14451 Co. Rd. 11 in Burnsville. The fee is \$6 and includes a box lunch. Send checks to ARC Suburban, 14451 Co. Rd. 11, Burnsville, MN 55337. For more information, call Marianne Reich at (612) 431-3700.

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PROMISES TO KEEP: SUPPORTED EMPLOYMENT FOR PERSONS WITH SEVERE DISABILITIES

"There is significant documentation of a disturbing trend--individuals with severe and profound disabilities have yet to benefit from (supported employment) opportunities to any significant degree." This observation was recently stated by John Kregel and Paul Wehman, Virginia Commonwealth University, in an article "Supported Employment: Promises Deferred for Persons with Severe Disabilities," *Journal of the Association for Persons with Severe Handicaps*, Winter 1989, pp. 293-303.

The authors implore that supported employment must become more than a program that serves individuals with mild or moderate mental retardation who have previously attended sheltered workshops or other adult day programs. Kregel and Wehman also provide some immediate steps to be taken to ensure that individuals with severe and profound disabilities are not excluded from these programs.

Kregel and Wehman reviewed the literature and history of supported employment as related to its application to persons with severe and profound disabilities. "During the 1970s," they noted, "systematic training technologies were developed and successfully used to enable persons with severe and profound mental retardation to perform complex vocational tasks previously felt to be far beyond their capabilities." With the success of providing intensive training in competitive employment settings, working primarily with individuals with moderate mental retardation, this soon led researchers to reexamine previous beliefs regarding the vocational potential of persons with severe and profound disabilities. This realization was described by F. R. Rusch and D. E. Mithaug (1980): "As we have learned about improved technologies to train complex vocational skills and about effective procedures to manage inappropriate behaviors, we have come to believe that even the person with the most severe retardation has an untapped vocational potential that can be translated into productive and independent work." (*Vocational training for mentally retarded adults: A behavior analytic approach*. Champaign, IL: Research Press, p. xv)

By the early 1980s, "Day activity and work activity programs were no longer viewed as the vocational alternatives of choice for persons with severe disabilities," Kregel and Wehman stated. "These programs were criticized for their segregated nature, the inconsequential wages earned by program participants, and their failure to prepare individuals for less restrictive, integrated employment options," the authors continued. Likewise, "vocational rehabilitation programs were criticized for excluding persons with severe and profound mental retardation from services, based upon a perceived lack of potential for achieving gainful employment," they added.

Through the efforts of advocates and the continuous growth of successful employment programs for persons with severe disabilities, coordinated federal initiatives were launched in the mid-1980s, including:

- Developmental Disabilities Act of 1984 (P.L. 98-527)-- supported employment was established as a priority area of activity for all developmental disabilities councils;
- Systems change demonstration projects in 27 states were funded by the Office of Special Education and Rehabilitative Services (OSERS) and the Administration on Developmental Disabilities (ADD);
- The Vocational Rehabilitation Act Amendments of 1986 (P.L. 99-506) fully incorporated supported employment into the vocational rehabilitation system by: a) modifying the prior definition of eligibility, b) providing funds for personnel preparation activities, c) authorizing demonstration programs, and d) establishing a specific funding stream that provided formula funding to promote the establishment of comprehensive supported employment programs in all states and territories.

Included in these innovations, as envisioned by policymakers and advocates, was the target population of persons with severe disabilities; persons who were previously excluded from any type of meaningful employment, as stated in the Vocational Rehabilitation Act of 1986:

The supported employment program is intended to provide services to individuals who, because of the severity of their handicaps, would not traditionally be eligible for vocational rehabilitation services. Individuals who are eligible for services under the program must not be able to function independently in employment without intensive ongoing support services and must require these ongoing support services for the duration of their employment. Such term includes transitional employment for individuals with chronic mental illness. (P.L. 99-506, Title I, Sec. 103,i)

For this study, Kregel and Wehman attempted to answer these questions: Who is participating in supported employment? To what extent is supported employment benefiting those individuals the program was developed to serve? What are the reasons that individuals with severe or profound disabilities are only minimally participating in supported employment at the present time, and what modifications are required to increase the participation of these persons in the program? The extent of supported employment participation by individuals with severe or profound disabilities was investigated through an analysis of the employment histories and functional characteristics of 1,411 individuals involved in supported employment programs in eight states.

Results indicated that individuals currently participating in supported employment possess very limited previous employment experience, yet did not possess functional characteristics indicative of individuals with

severe or profound disabilities. Persons with severe or profound disabilities were found to be minimally represented in current supported employment efforts, representing less than 8 percent of all individuals investigated. "Individuals with mild or borderline mental retardation represented an alarmingly large percentage of the population," the authors stated. They added that their analysis was not meant to imply that the individuals represented in the data base were inappropriate for, or should not be served in, supported employment, but that "(these programs) are not yet serving the entire range of individuals for whom supported employment was intended."

Kregel and Wehman noted that tremendous progress has been made in improving employment opportunities for persons with severe disabilities in the last decade. "However," they added, "it is critical that action be taken now to ensure that persons with severe or profound disabilities are not excluded from supported employment programs as they were from other vocational alternatives in the past:

1. It cannot be assumed that an effective technology currently exists that allows the independent participation of persons with severe and profound disabilities in integrated work environments . . . the question is how can we enable them to benefit from supported employment? The professional literature contains very few examples of clinical demonstration that empirically document successes. The development, demonstration, and dissemination of new and innovative service delivery models should be promoted and encouraged by funding agencies. The spirit of experimentation prominent during the late 1970s and early 1980s should be renewed. New technologies must continue to emerge, personnel preparation must be enhanced, and new approaches tested in order for supported employment to achieve its intended purposes.

2. The practice of attempting to first serve persons with mild disabilities before serving persons with severe handicaps, based on the erroneous belief that the latter group will be less likely to succeed, is still strongly prevalent. Emphasis must continue to be placed on methods to eliminate the philosophical and social barriers that artificially limit supported employment participation.

3. Federal and state policies must effectively encourage the incorporation of individuals with severe and profound disabilities into supported employment. At least three innovative policy approaches should be attempted and evaluated: a) state and local policies should be developed that explicitly identify supported employment as the preferred employment alternative for individuals with severe and profound disabilities; b) discretionary funds and program start-up grants should be directed toward programs designed to benefit individuals with severe and profound disabilities (it is no longer necessary to "demonstrate" that individuals with moderate mental retardation, for example, are able to succeed in integrated employment settings); and c) variable funding rates should be established to provide fiscal incentives for programs that serve persons with severe and profound disabilities (funding that will also encourage local flexibility in the design and delivery of services).

The authors concluded, "Steps must be taken immediately to ensure that individuals with severe and profound disabilities are not excluded from these programs."

Copies of the article may be obtained from: The Association for Persons with Severe Handicaps (TASH), 7010 Roosevelt Way N.E., Seattle, Washington 98115. Tel. (206) 524-7341.

MINNESOTA RESOURCE NETWORK ON SUPPORTED EMPLOYMENT HAS FULL AGENDA

The Minnesota Technical Assistance Resource Network on Supported Employment has begun its third year of assisting service providers. The Network is a collaborative project of the University of Minnesota's Institute on Community Integration at the University of Minnesota and the Division of Rehabilitation Services, Department of Jobs and Training. Highlights of the Network's 1990 agenda include:

Job coach training within the higher education system: During the past year, Network staff assisted in the offering of three job coach training courses within the Minnesota Technical College system. This year, job coach training will be offered again, with plans for the establishment of additional sites currently underway.

Specialized training events and technical assistance in collaboration with the Minnesota Alliance for Training and Technical Assistance: Series Three training events are presently being formalized, with plans for financially-assisted subsequent technical assistance to be offered to any participating agency.

Technical assistance to persons with severe disabilities: Plans include the completion of a multi-year study of persons with severe disabilities and the impact of supported employment upon their lives. Various assessments have been used to evaluate changes in productivity, socialization, and independence. A monograph profiling each of the subjects will be made available at the end of the current contract year.

Ongoing technical assistance resources: The Network continues to compile and make available a wide variety of print and video resources for use by any supported employment agency within Minnesota. Consultants from throughout the country are kept on file for accessing technical assistance through phone contact or on-site visits.

Information and dissemination: The Network continues to produce quarterly issues of *What's Working in Supported Employment*, a compilation of best practices and strategies contributed by field professionals. In addition, a periodic Job Coach News Brief offers job coaches and employment specialists insight into current training opportunities and other resources to assist them in their work. Resource guides will be made available during the next few months.

For more information, contact: Ron Erickson, Institute on Community Integration, University of Minnesota, 6 Pattee Hall, 150 Pillsbury Drive Southeast, Minneapolis, Minnesota 55455. Tel. (612) 624-0232.

GOVERNOR APPOINTS NEW MEMBERS TO PLANNING COUNCIL ON DEVELOPMENTAL DISABILITIES

Governor Rudy Perpich has recently appointed several new members to serve for a term of three years on the Governor's Planning Council on Developmental Disabilities:

Catherine Baudeck, Minnesota Board on Aging, Hibbing;

Lois Holleman, parent, Lake George;

Byron Johnson, M.D., provider, Roseville;

David Schwartzkopf, Director, Division of Rehabilitation Services, St. Paul; and

Patricia Tietz, parent, Shakopee.

In addition, the Governor has appointed a new Council Chair, Duane Shimpach from Fairmont, and reappointed the Vice Chair, Jeannette Kester, Sandstone.

The Governor's Planning Council on Developmental Disabilities is responsible for supervising the design and implementation of a state plan, which measures the quality, extent, and scope of needed services for people with developmental disabilities. Under the current plan, the Council has selected the following priority concern: "Increase accountability to individuals with developmental disabilities of all ages to improve independence, productivity, and integration into the community."

Two publications are available which describe the philosophy and direction of the Council: 1) *Two-Year Transitional Plan: State of Minnesota Developmental Disabilities: Accountability*, and 2) *1990 Report: The Heart of Community is Inclusion*. Contact: Governor's Planning Council on Developmental Disabilities, 300 Centennial Office Building, 658 Cedar Street, St. Paul, MN 55155. Tel. (612) 296-4018, or (612) 296-9962 (TDD only).

STUDY OF JUVENILE OFFENDERS INITIATED

The University of Minnesota's Institute on Community Integration, together with the Minnesota Citizen's Council on Crime and Justice, recently received a grant from the Nevin N. Huestad Foundation to examine issues related to juvenile offenders with developmental disabilities. The primary objectives of this six-month project are to: conduct a preliminary investigation of how Minnesota's criminal justice system deals with persons with developmental disabilities; create a list of resources and services for criminal justice professionals to help them effectively and appropriately deal with individuals who are mentally challenged; report findings of the study along with recommendations; and disseminate the report to criminal justice policymakers, practitioners, other appropriate organizations, and interested citizens. For more information about the project, contact: Dave Johnson, Institute on Community Integration, University of Minnesota, 6 Pattee Hall, 150 Pillsbury Drive, S.E., Minneapolis, MN 55455. Tel. (612) 624-1062.

MEDICAL TECHNOLOGY ASSISTANCE REVIEW PANEL ESTABLISHED

In 1988, the Minnesota Department of Health released a special study to the Minnesota Legislature on third party payor reimbursement of home health benefits for technology assisted individuals. A major recommendation of that study was to establish a voluntary, interdisciplinary expert advisory and review panel on dispute resolution of home health care benefits. In 1989, the Medical Technology Assistance Review Panel (MedTARP) was created.

MedTARP is a voluntary six member group which reviews cases where there is a dispute over: a) discharge planning; b) the home health care benefit package; and/or c) changes in home care service delivery or reimbursement for technology assisted individuals.

A technology assisted person is one who has a chronic disability, requires routine use of a medical device to compensate for the loss of a vital body function, and who requires substantial and ongoing care or monitoring by trained individuals.

Any Minnesota resident under 65 years of age who is technology assisted and currently has private health insurance is eligible for Panel Review. Note that public programs such as Medicaid, Medicare, and Services for Children with Handicaps have their own appeal mechanism and cannot be reviewed. More information and application procedures

are available from: MedTARP, c/o PATHFINDER, 5000 West 39th Street, Minneapolis, MN 55416. Tel. (612) 927-3850.

PUBLICATIONS/RESOURCES

New Ways Magazine is new quarterly publication intended "To Bring a Better Life to People with Mental Retardation." Feature articles on innovations are contributed by guest writers throughout the country. For subscription and other information, contact: New Ways Magazine, P.O. Box, 5072, Evanston, IL 60204.

Action for Inclusion: How to Improve Schools by Welcoming Children with Special Needs into Regular Classrooms. J. O'Brien & M. Forest, with J. Snow & D. Hasbury. Centre for Integrated Education, 1989. "Inclusion is the right thing to do," declare the authors of this guide to integrated classrooms. "It challenges everyone concerned with education to change their ideas about the place of children with special needs by changing routine practice and welcoming all children into each classroom--it demands new learning and hard work." The practical lessons in this manual outline these demands and share what has been learned about how to meet them. Contact: Centre for Integrated Education, 35 Jackes Avenue, Toronto, Ontario, Canada M4T 1E2. Tel. (416) 923-3591.

Interagency Planning for Transition in Minnesota: A Resource Guide, 1990, Minnesota Department of Education and the Institute on Community Integration, University of Minnesota. This manual is designed to assist Community Transition Interagency Committees in establishing, managing, and maintaining an active approach to interagency planning for assisting youth with disabilities in their transition to quality adult lives. Contents include: an overview of transition in Minnesota, establishing an interagency committee, assessing community needs, working effectively together, community action planning, and national and state resources. For purchase information, contact: Sandy Thompson, Institute on Community Integration, University of Minnesota, 6 Pattee Hall, 150 Pillsbury Drive SE, Minneapolis, MN 55455. Tel. (612) 624-4848.

CONFERENCES/WORKSHOPS

May 23, 1990

The Governor's Advisory Council on Technology for People with Disabilities is sponsoring a forum on "Research and Development for People with Disabilities," to be held at the Plymouth Place Hotel, Plymouth, Minnesota. The forum will highlight: demographics and disability; assistive technology for persons with hearing impairment; neuromuscular stimulation; speech and cognition impairment; research and development in gerontology; advancements in technology for persons with visual impairments; and sources of financial assistance. In addition, the Governor's Awards for Technology to Assist Individuals with Disabilities will be presented. The conference will run from 8:00 a.m. to 4:30 p.m., and includes a luncheon. The registration fee is \$10.00. Pre-registration required. Call: (612) 296-2771.

June 20-22, 1990

"Mission POSSIBLE: Building Community through Empowerment and Inclusion," is the theme of the Summer Conference cosponsored by the Minnesota Developmental Achievement Center Association, Minnesota Association of Rehabilitation Facilities, and the Staples Technical College. The Conference will be held at Madden's on Gull Lake, Brainerd. For other information, contact: MARF, 1821 University Avenue, South, St. Paul, Minnesota. Tel. (612) 646-0900.

The State Developmental Disabilities (DD) Program Office has acquired several education, training and resource materials. The following materials may be borrowed from the State Office only, located at the address on the front sheet of the State Supplement section of this newsletter. Tel. (612)296-4018.

LENDING LIBRARY SELECTIONS

Transitions to Adult Life for People with Mental Retardation: Principles and Practices. B.L. Ludlow, A.P. Turnbull, and R. Luckasson (Eds.). Paul H. Brookes Publishing Company, 1988. This book examines the broad policy issues and sets forth a plan for developing and implementing transition plans for youth with developmental disabilities; plans for leaving school to live, work, and play in integrated settings. This book is designed for both policymaker and practitioner; it is intended to offer "how to" suggestions for designing, implementing, and evaluating transition programs for real people in real communities. Contents includes: 1) concepts and trends, such as transitions across the lifespan, coming of age, letting go, and integrated curriculum; 2) programming goals and strategies, such as independent and supported living, community participation, and productive employment; and 3) legal, administrative, and policy issues. The Appendix provides a number of helpful resources: an annotated bibliography, media resources, and a program directory of noteworthy models throughout the country.

Disability and the Family: A Guide to Decisions for Adulthood; H. Rutherford Turnbull III, Ann P. Turnbull, G.J. Bronicki, Jean Ann Summers, and Constance Roeder-Gordon (Eds.); Paul H. Brookes Publishing Company, 1989. This volume provides guidelines for making plans that are legally and financially effective, that consider real-life choices and preferences, and that take into account the social, leisure, residential, and vocational options that can help ensure a desired quality of life for persons with disabilities and their families. Section I explores the meaning of mental competence and legal issues based on the person's ability to make decisions. Part II provides information about government benefits that can help to implement plans. Section III discusses the concept of choice and how individual preferences relate to interpersonal relationships and selection of residences, jobs, and leisure activities. Section IV provides a discussion of how to encourage people to be their own advocates. The authors maintain that future planning can improve the quality of life for all family members.

Metropolitan Council DD Program
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St. Paul, MN 55101

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A NEW DECADE. THE 1990s: BUILDING INCLUSIVE COMMUNITIES

Belonging at School and at Home, A Place for Jenna

Jenna is a pretty little seven-year-old with dark brown eyes and long dark brown hair tied up in pigtails with pink ribbons. Her smile with pearly white teeth is engaging. Jenna is described by her mom Cindy as cute, lovable, charismatic, accepting of herself and others, determined and cheerful.

Jenna attends Eastern Heights Elementary School in St. Paul where she is finishing first grade. She lives with her mom and 10-year-old brother in a home that was recently adapted to meet her needs. In early May the home was featured on *The Home Tour*. Jenna needed the adaptations to her home because she has cerebral palsy and was becoming increasingly frustrated trying to get around her home in her wheelchair.

Premature birth and probably too little oxygen immediately after birth may have caused the disability. Anyway, Cindy knew from birth that Jenna would require special services. From about three months of age she was involved in a school-

sponsored, parent-infant program where Jenna received therapies.

At age four Jenna was in a pre-kindergarten program with other children with severe disabilities. She was the only one who could talk. When she attended with her mom a program at her brother's school, Cindy saw how the other school kids interacted with Jenna and how Jenna responded to them. It was then that Cindy decided she wanted Jenna to be in a school with regular kids. She'd been bitten by the "integration bug."

Getting Jenna into her neighborhood school was a long and difficult ordeal. Cindy very often felt totally alone because there was no support from professionals or teachers or even from parents of other children with disabilities. Fortunately she had the support of family and friends.

The school assessed Jenna and determined that she should remain for another year in the pre-kindergarten program. She had failed the basic benchmarks which would allow her to attend kindergarten. Jenna, however, did not like the program and cried every day her mother put her on the bus. Cindy noted that some children were still in the pre-kindergarten program at ages eight and nine. She decided she wasn't going to allow that for her daughter. She wanted Jenna to attend regular

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kindergarten at her neighborhood school. Cindy asked her son's kindergarten teacher to give Jenna the same assessment and Jenna only missed two of the benchmarks. This became her ammunition to gain Jenna's admittance to kindergarten. Cindy knew all along that Jenna was not severely retarded. In fact, she isn't retarded at all.

Cindy asked Legal Advocacy to attend several school meetings with her over the summer. Legal Advocacy helped her clarify her vision about what she wanted for Jenna. At the third meeting with the school professionals, Eastern Heights people attended and welcomed Jenna to their school. Jenna began kindergarten in the fall of 1988.

Jenna has done extremely well in school and has made a lot of friends. In fact, she's having trouble deciding who to invite to her "jacuzzi party" for her birthday next month. Jenna started Brownies this year and recently went to camp with them for the weekend and on a roller-skating party. She loves water skiing and accomplishes this by wrapping herself around the "skier." She was a part of her school's Christmas program, had a Halloween party with kids from her class, and participated in a regular community recreation T-ball team last summer. A few weeks ago at the Festival of Nations, she participated in her own German costume with a German dance group. At home she loves her computer and knows the keyboard and uses programs borrowed from PACER. She also loves her new puppy and playing in her sandbox with other kids from the neighborhood.

Cindy says that one of the things that has supported Jenna to be integrated into so many activities is the ingenuity and willingness on the part of people in the school, in the Brownies, in the German dance group and in T-ball to find ways to include her, all on their own. According to her, "big movements have happened in quiet ways."

One of the real challenges to keeping Jenna at home and in her community was to make modifications to their home to appropriately meet Jenna's needs as well as the needs of the rest of the family. Cindy is a low-income, single parent. The remodeling project took one and one half years to accomplish, but Jenna can now enter the front door in her wheelchair and has her own large bedroom and bath with a jacuzzi equipped with a hydraulic lift and accessible toilet. Cindy designed the addition as

a class project for a course she was taking.

Help was obtained from several sources. One was a St. Paul Home Loan Fund deferred loan for \$12,000. If Cindy resides in her current home for at least 10 more years, the loan does not have to be repaid. This is a program for low-income homeowners who need improvements for health and/or safety reasons.

Another source of money was the Minnesota Housing and Finance Agency where she obtained a \$9,000 low-interest, home-improvement loan for 15 years from the Home Loan Fund.

Cindy also negotiated hard with the various contractors to convince them to lower their prices for this project. She was able to do some of the work with friends and family to further reduce the overall cost.

A final source was the program called CADI (Community Alternatives for Disabled Individuals) which provides funds for people with disabilities in need of services or equipment. It assists people to live outside institutions.

The total cost for the renovation project was \$24,200 and Jenna will be able to use the home her entire life. This is a very small cost when considering the price tag of institutional care at \$60,00 per year.

Jenna now has the opportunity for growth, happiness and independence within a family setting and going to her neighborhood school and doing regular "kid things" because some special programs allowed her to access some technology and adaptations to make that possible.

FOR YOUR INFORMATION

Community Services Program

~~West-Hennepin Community Services (WHCS)~~, located in Hopkins, Minnesota, provides community-based support and training for persons with developmental disabilities and their family members. WHCS offers a wide range of programs and services such as counseling, support groups, adaptive recreation and education classes, integration assistance and semi-independent living skills programs. All services are designed to meet individual and family needs through community-based programs serving primarily West and

Northwest Hennepin County. Through participation in the programs the center assists individuals in developing skills and attitudes which will maximize independence and promote active participation into the larger community. Programs are run on a quarterly basis and pre-registration is generally required. Please contact Mary Mullin at 933-9150 to receive a copy of the current program brochure and also to be placed on the mailing list.

Brain Injury Library

The Josephine Kretsch Brain Injury Library is a non-profit resource center for librarians and individuals seeking information about cerebral palsy, coma/head trauma, autism, Down's syndrome, learning disabilities, reading problems and issues relating to brain injury. The library has announced free Traveling Mini-Library Kits available for a six-week loan. Each mini-library or kit contains brochures, posters, a master bibliography and 15-20 books focused on specific issues relating to brain injury. The following kits are available: autism, allergies, brain-injured children, brain injury in adults, cerebral palsy, children's books about disabilities, coma and head trauma, computers and disability, developmental disabilities, premature infants/toddlers, the brain, and vision, auditory and speech development. To order a kit with postage paid one way, contact: Kretsch Library, 5034 Oliver Av. N., Minneapolis, MN 55430. (612) 521-4245.

Art Center Programs for People with Disabilities

The Art Center of Minnesota, located in Wayzata, is making headway toward becoming completely handicap-accessible. The Center, located near Lake Minnetonka, offers courses in the arts (visual and performing arts as well as language, culture and writing) to children, teens, adults and seniors. Classes are being designed to accommodate people with special needs and steps are being also taken to recruit people with disabilities to take the classes. Modifications are planned for the building to make it fully accessible throughout. For further information on the programs offered by the Center, contact the Art Center of Minnesota, 2240 N. Shore Dr., Wayzata, MN 55391. (612) 473-7361.

Med-TARP

The Medical Technology Assistance Review Panel (Med-TARP) has been established to resolve home care benefit payment disputes between consumers who are technology assisted (or the families) and insurers. Persons who are technology assisted have a chronic disability and require the use of a medical device to assist in life-sustaining care (e.g. ventilator, oxygen, tube feeding). Med-TARP reviews cases where there is a dispute over hospital discharge planning, the home care benefit package, or changes in reimbursement of home-care services by the consumer's insurer (private health insurance plan). The voluntary six-member panel includes two insurer representatives, two providers and two consumers. Any Minnesota resident under 65 years of age who is technology-assisted and had private health insurance is eligible for Med-TARP once the grievance process within his or her insurance plan has been completed. For more information, contact Med-TARP, care of Pathfinder, 5000 W. 39th St., Minneapolis, MN 55416. (612) 927-3850.

RECREATION

Sixth Annual SILS Dance

A springtime dance for individuals in independent and/or semi-independent living situations (SILS) will be held on Friday, June 15. Pillsbury House and Southside Services are co-sponsoring the event. The dance will be held at the Falldin American Legion Post 555, 3141 Central Av. NE, Minneapolis, from 8 to 10 p.m. A nominal entrance fee will be charged. Free food, door prizes and band music will be offered. Flyers will be mailed to all SILS providers in the Twin Cities Area to distribute to people receiving services from them. For more information, contact Jerry or Rich at Southside Services, 721-1696 or Jim at Pillsbury House, 824-0708.

EMPLOYMENT OPPORTUNITIES

Executive Director

Individual would be responsible for the overall operation of a non-profit agency which provides adult day services and employment placement/support for 110 persons with disabilities in the East Metro Area. Duties include supervision

of 30 employees, program services, annual budget development and monitoring, contract management, compliance with government regulations, facility management and liaison to board of directors. Position requires a BA/BS degree, MA preferred, five years management experience, knowledge of Rule 38. Send resume by June 30 to Joyce Lang, ESR, P.O. Box 28055, St. Paul, MN 55128-0055.

Program Counselor

Thomas Allen, Inc. has openings for the position of program counselor. Locations with openings include New Brighton, St. Louis Park, Burnsville, Bloomington, West St. Paul, South St. Paul, Shakopee and Chaska. Shifts include mornings, afternoons and/or weekends. The pay is \$6.50 to \$7 per hour. For further information call the personnel office at 450-1802 or the 24-hour hotline at 450-7271.

Developmental Disabilities Services Director

Opportunity to provide leadership and resource in Lutheran Social Service of Minnesota, a state-wide agency committed to normalization and community integration of persons with developmental disabilities; office in Minneapolis/St. Paul area. Application available through Joanne Negstad, Vice President, Program, 2414 Park Av. S., Minneapolis, MN 55404. Completed application due by June 15.

WORKSHOPS/CONFERENCES

June 15

Advocating Change Together, Inc. (ACT) and Kaposia, Inc. are co-sponsoring a workshop titled **"EMPOWERMENT: Self-Advocacy in the Workplace."** The workshop is designed to provide participants with a real understanding of self-advocacy and the practical application of empowerment in the workplace. Session topics include: the history and philosophy of self-advocacy, the role of the advisor to self-advocates, how to encourage self-advocacy on the job, and tools for empowerment at work. The workshop will be held at the Sheraton Midway, 400 N. Hamline, St. Paul, MN, from 9 a.m. to 3:30 p.m. The fee is \$30 and includes lunch. For further information or to register, call Libby Turner at (612) 641-0297. Registration deadline is June 11.

June 28-29

The 1990 workshop series of the American Association on Mental Retardation (AAMR), entitled **"Designing an Augmentative and Alternative Communication System for Persons with Severe Disabilities"**, will be held at the Hyde Park Hilton, Chicago, Illinois. The workshop series is co-sponsored by the Institute on Community Integration, University of Minnesota, and the Minnesota Governor's Planning Council on Developmental Disabilities. Contact: Paula Hirt, Director of Training, AAMR Training Institute, 1719 Kalorama Road, NW, Washington, D.C. 20009. Tel. 1-800-424-3688, toll-free.

July 13-14

The First Annual Conference of the **Association for Persons in Supported Employment (APSE)** will be held at the Radisson Hotel in Denver, Colorado. For registration information, contact: APSE, 5001 West Broad St., Suite 34, Richmond, Virginia 23230.

July 29-August 1

"Partnerships for Progress IV" is a national conference on P.L. 99-457, Comprehensive Services for Infants, Toddlers, and Preschoolers with Special Needs and Their Families. It is sponsored by the Federal Interagency Coordinating Council, and will be held at the Hyatt Regency Crystal City, Arlington, Virginia. Contact: National Early Childhood Technical Assistance System, CB #8040, Suite 500, NCNB Plaza, University of North Carolina, Chapel Hill, North Carolina 27599. Tel. (919) 962-2001.

August 9-11

"1990 Futures Conference: Developing Partnerships for Progress" of the National Association of Rehabilitation Facilities will be held in Indianapolis, Indiana. For registration and other information, contact: NARF, P.O. Box 17675, Washington, D.C. 20041. Tel. 1-800-368-3513.

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WHAT LIES AHEAD IN THE 1990s? TOWARD A 'MOSAIC SOCIETY'

"Rising levels of education, increased ethnic diversity, a growing population of elderly individuals, more single-person households, and other diversity-related trends are moving American society away from 'mass society' toward a 'mosaic society... The mosaic, however, is not static; rather, it is similar to an ever-changing kaleidoscope." This observation was stated in a recent publication, *What Lies Ahead: Countdown to the 21st Century*, by the United Way of America. The Environmental Scan Committee that prepared this report studied the developments in the social, economic, technological, political, and philanthropic arenas. The results are both wide-ranging and germane to all human service organizations. As noted by William Aramony, President, "Reports such as this one help us to focus our vision on the opportunities and challenges that lie ahead and to develop plans to meet them."

The Environmental Scans Committee (consisting of members with experience in business, medicine, philanthropy, and forecasting) specified nine "changedrivers" about social, economic, political, technological, and philanthropic trends. Changedrivers are "those forces which will be quite disruptive; at the same time, offer opportunities to strengthen America's social and economic fabric," the authors reported. Following are highlights about each trend:

The Maturation of America: The baby boom generation is moving into their prime family-, household-, and asset-formation phase. With the "graying of America," there is growth of the age-65-and-over population, which is more active and more affluent. There will also be an accompanying maturation and sophistication of tastes. "The U.S. is leaving an era obsessed with youth, and moving into one that will be more realistic, more responsible, and

more tolerant of diversity," the authors stated. Other noteworthy maturational trends include:

- * **Social:** 1) There will be continued declines in the proportion of children and young adults in the population with sharp increases in the proportion of middle-aged (35 to 45) and those over age 75; and 2) Colleges and universities will increasingly recruit older Americans, ages 65 and older, as students.
- * **Economic:** 1) A better-educated labor force will be necessary to increase U.S. economic productivity; 2) A new corporate "elite," and the highly educated "gold collar" knowledge worker will emerge; and 3) Businesses will increasingly offer older workers and retirees flexible work schedules and retirement options in an effort to reverse the trend toward early retirement.
- * **Political:** Political activism will be more pragmatic and measured, reflecting the aging of society.
- * **Technological:** Research will discover more ways to ease the effects of aging.

The Mosaic Society: Referred to by Alvin Toffler, author of *Future Shock*, as "demassification," technology will enable products to be customized for each of the parts of the mosaic society, further reinforcing their distinctive identities.

- * **Social:** 1) Besides a growth of the U.S. population through legal and illegal immigration, there will be continued greater proportional growth of minorities; 2) Schools will be affected by increasing minority populations, will increasingly use alternative educational options (such as year-round schedules and magnet schools), and they will use alternative methods of teacher certification to alleviate teacher shortage.
- * **Economic:** 1) Both the very large (multinational)

and the very small firms will add substantial employment, with mid-sized firms to grow less quickly; 2) The urban, minority underclass will continue to grow; 3) The labor force will be increasingly multicultural and multilingual; 3) Women's representation in top corporate positions will increase substantially.

- * **Political:** 1) Decentralization of government will continue at a slower pace; 2) There will be increased growth (in numbers and influence) of special-interest groups; and 3) Asians, Blacks, and Hispanics will seek greater political influence commensurate with their growing share of the population.
- * **Technological:** Advances in information technology will enable individuals to obtain products, services, publications, and information which are more narrowly targeted at their particular ethnic characteristics, economic status, and personal preferences.

Redefinition of Individual and Societal Roles:

There will be a blurring of the boundaries which have traditionally defined the roles of the public sector versus the private sector, as well as those which have set the boundaries of individual versus institutional responsibilities. The federal budget deficit will continue to constrain federal action on social problems, and both the federal and state governments are contracting with private-sector firms to perform many functions which have traditionally been carried out by government. Business will be more directly involved in social issues (such as education, illiteracy, substance abuse, and AIDS).

Individuals will be less willing to wait for large institutions to provide opportunities, and more willing to act on their own, such as a growing emphasis on wellness activities as an example of the shift away from doctors and hospitals. Individuals will also take on more responsibility for their employment and careers, i.e. growth in entrepreneurial activity, self-employment, and multiple careers.

The Information-Based Economy: The spread of information and communications technology is creating an information-based economy, which is structured differently from the current industrial economy. Business will operate more through networks--rather than be consolidated under one

roof--to produce a growing range of products and services that are geared less for the masses and tailored more toward the individual. Although there will be an increasing concern about scientific literacy, by the year 2000, in some urban areas, virtually every individual will have contact with computers in the home or workplace.

Other innovations will include: increased use of information technology as teaching and learning aids; video, audio, and data transmission to be integrated into a single, fiber-optic telephone system; "mobile communications environment" to develop and be institutionalized as portable phones, facsimile machines, beepers, and computers to make 24-hour accessibility possible; digital sketch pads, optical scanners, and voice recognition systems that will be used as "keyboardless" data entry devices; continued factory automation; mapping of the human genome to improve the ability to diagnose serious illness; and biology-based industries will grow in economic importance. In addition, electronic gadgetry will quicken the pace of American life. Cable television will offer more sophisticated features and draw a larger audience. Information overload will bring about concern for the quality of information. Concern will grow about the health effects of working at computer terminals, including stress, eye damage, and hand muscle problems.

Globalization: The movement of products, capital, technology, information--and ideas--around the world are having several significant effects. (1) There is increasing foreign ownership of the U.S. industrial base, and a growing presence of U.S. firms in foreign countries. (2) The relative economic power of the U.S. is declining as other nations develop mature industrial economies. (3) U.S. consumers are experiencing more cultures through travel, imports, immigration, international organizations, and the media--a globalization of tastes and ideas is occurring. (4) Americans are directing their volunteer time and their philanthropic dollars toward a range of global, as well as national causes. (5) Meanwhile, foreign-owned firms are playing a growing role in American philanthropy.

Economic Restructuring: Brought about by global economic competition, deregulation, new information technologies, and diverse and changing consumer tastes, businesses are forced to restructure at many levels: 1) newly industrialized countries are emerging as robust economies; 2) entire industries

are being globalized and restructured as new entrants and new technologies change the rules of the game; 3) large corporations are cutting management layers and operating more like networks rather than hierarchies.

Personal and Environmental Health: Quality-of-life issues, particularly the health of the individual and the state of the environment, are beginning to emerge as key areas of public concern, i.e. global warming from the "greenhouse effect" and ozone depletion, and the link between personal behavior and disease risk.

Family and Home Redefined: In a rapidly changing, often chaotic outside world, the family will grow in importance as a stabilizing force. Yet, at the same time, the evident stresses on family life may make the family less able to fulfill its support-giving role without help from outside the family structure. Government assistance with child care is one example of such help. Family violence (child, spouse, and elder abuse) will remain a critical problem. Income inequality among families will increase, with two-income households gaining and single-parent households falling behind. There will be continued growth in the number of self-employed; many to work at home using computers. On the political scene, national and/or state legislative action are most probable around issues involving children (e.g. child care and poor children), education, welfare reform, and long-term care.

Rebirth of Social Activism: After a decade of concentration on business and economic growth, the public-agenda pendulum is swinging decisively in the direction of social concerns. Environmental degradation, deterioration of public infrastructure (such as roads and water-supply systems), pervasive homelessness, lack of affordable housing, racial tensions, and extensive child poverty are some of the issues which are gaining increased attention. There is likely to be less tolerance for business actions which the public perceives as harmful to society, such as financial actions which harm the economy and pollution which threatens public health. More coalitions involving business, government, education, and the nonprofit sector will emerge to address social problems seen as beyond government's ability to address alone. There will likewise be an increase in state government influence, and a decline of federal influence over these issues.

Among the many recommendations to the United Way of America, the Environmental Scan Committee mentioned:

Americans are increasingly concerned about issues that face their community, such as drug abuse, AIDS, environmental pollution, the quality of public education, and the plight of the homeless. United Ways must remain sensitive to such concerns and, when appropriate, seek solutions through leadership in community problem-solving efforts and communicate what is being done to respond to the issues.

Copies of the report are available from: United Way of America, Attn: United Way Strategic Institute, 701 North Fairfax Street, Alexandria, Virginia 22314-9989.

SCHOOL INTEGRATION PROJECT FUNDED

The Institute on Community Integration, University of Minnesota, has received a grant from the U.S. Department of Education for a 3-year project entitled, Membership in Home Schools for Students with Severe Disabilities. The Institute, in collaboration with the Forest Lake Area School District, will provide in-service training and technical assistance regarding integrated education. The Project will result in an educational service system that includes and supports children with severe disabilities in their home schools and regular classes. The project design is based on system-wide participation and ownership of integrated education processes and outcomes. From school board members to peers without disabilities, all will play a role in shaping the integration and instructional strategies.

The Scandia Elementary School will participate during the first year of the project. A transition plan will be designed and implemented to return at least five children with disabilities to their home school. In succeeding years, additional elementary schools will participate, with the goal of full integration in each of the seven schools. Children and parents will participate voluntarily. For further information, contact Terri Vandercook, Project Director, Institute on Community Integration, University of Minnesota, Pattee Hall, 150 Pillsbury Drive, Southeast, Minneapolis, MN 55455. Tel. (612) 624-4848.

The State Developmental Disabilities (DD) Program Office has acquired several education, training and resource materials. The following materials may be borrowed from the State Office only, located at the address on the front sheet of the State Supplement section of this newsletter. Tel. (612)296-4018.

LENDING LIBRARY SELECTIONS

Teaching People with Developmental Disabilities, Oregon Research Institute, Research Press, 1988. This is a video training series designed to help teachers, staff, volunteers, or family members learn four behavioral techniques while teaching functional living skills. The series features four videotapes and four workbooks. Each video includes numerous scenes of actual training sessions in which teachers are shown working with students. A helpful narration offers valuable guidelines and points out the correct and incorrect use of techniques presented in the program. As an integral part of the program, the workbooks provide helpful readings, discussion material, and content review questions. The four-part series consists of: Tape 1, Task Analysis; Tape 2, Prompting; Tape 3, Reinforcement; and Tape 4, Error Correction.

It's Michael's Money: Innovative Training for Representative Payees, Kent County ARC, Inc., 1990. This videotape has two parts. Part I (15 minutes) provides an overview of the Social Security Representative Payee system, and it explores the value of choice making. It is designed to recruit new Representative Payees. Part II (30 minutes) uses a discussion group format to provide more detail about how to serve as a Representative Payee, focusing on technical, legal, and inter-personal considerations. The Social Security Administration uses a Representative Payee system for both Social Security Disability Insurance (SSDI) and Supplemental Security Income (SSI) if it has evidence that the person's impairments prevent adequate handling of money. The Representative Payee can be a relative, friend, agency, or court appointed representative. The importance of achieving a balance between the protection of and independence by the recipient is discussed.

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INFORMATION EXCHANGE

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Editor: Kay Zwernik*

**Metropolitan Council
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July 1990**

VOLUNTEERS NEEDED FOR METROPOLITAN COUNCIL'S DISABILITIES ADVISORY COMMITTEE

The Metropolitan council is taking applications from Twin Cities Metropolitan Area residents interested in serving on its Disabilities Advisory Committee.

The volunteer committee advises the Council on the needs of people with mental physical and developmental disabilities and helps coordinate planning to meet those needs.

The 25-member committee is made up of persons who have disabilities, their parents or guardians, service providers and the general public. Members serve three-year terms. There are eight vacancies to be filled.

The committee usually meets the third Tuesday afternoon of every other month. Members are expected to serve on subcommittees. They volunteer their time, but will be reimbursed for their expenses such as parking and transportation.

For applications or more information, call Council staff Kay Zwernik at 291-6364. For an application form, call Stephanie Andress at 291-6427. Appointments will be made by the Council on

September 27, and the new terms will begin Oct. 1.

The functions of the former Developmental Disabilities Advisory Committee are being expanded to include all disabilities. This change will assist the Metropolitan Council to better plan for the entire disability community.

A NEW DECADE THE 1990s: BUILDING INCLUSIVE COMMUNITIES

What We Are Learning About Friendships

by Angela Novak Amado, Ph.D.

More and more people are concerning themselves with the issue of friendships between people with and without disabilities. Through work, discussions and thinking, the following are some insights and random thoughts about friendships and our role in fostering them.

The Most Important Thing in Life Is Being Cared About

If, in some bizarre political-control experiment, you were told that everything in your life would be taken away, except one thing, what would you choose to keep? Most people are willing to give up their jobs, their homes, their status, and choose as the most

Activities, notices, services, products, etc. mentioned in this publication are for information purposes only and do not imply endorsement by the Development Disabilities Programs of the Metropolitan Council and the State Planning Agency.

important thing: the people with whom they're close. We get our sense of self, self-esteem, confidence, and awareness of ourselves and the world, through being touched, stroked, knowing and trusting that there are others who care about us. Being cared about and having close friends is not only very important to almost everybody; it's also critical simply to being alive.

Numerous scientific studies have documented the terrible health effects of loneliness. James Lynch, in *The Broken Heart: The Medical Consequences of Loneliness*, documents that people who are more alone, such as single, widowed, and divorced people, are far likelier prey to disease than married folks. He says, "There is a biological basis for our need to form human relationships. If we fail to fulfill that need, our health is in peril." James House, in *Science* magazine, reviewed 20 years' worth of studies and said, "The data shows that people who are isolated are twice as likely to die over the period of a decade or so as are others in the same health...After controlling for the effects of physical health, socioeconomic status, smoking, alcohol, exercise, obesity, race, life satisfaction and health care, the studies found that those with few or weak social ties were twice as likely to die as were those with strong ties." People who do not have close contact with others or who have no one to share their private feelings with, are at the most risk. Social isolation is as great or greater a mortality risk than smoking.

The map of the relationship networks of a typical person is very different than the map of relationships for a person with disabilities. The person with disabilities almost universally has far fewer relationships, in far fewer areas of life. Most of the relationships are in three areas: family, people who are paid to be with them, and other persons with disabilities. There are thousands of ways to come to know and understand the genuine experience of social isolation for many persons with disabilities. One small example that probably many people have had is the experience of walking into a DAC or large group home, and suddenly being surrounded by a large handful of people, all wanting to shake your hand, say "Hi," and find out your name. That need for contact, for being known, for being in relationship, is universal to all of us.

Why, in an industry so governed by Health Care Plans, Abuse Prevention Plans, and the requirement

for "active treatment," is the need for social relationships so relatively ignored? What would happen if we put as much attention, energy, and regulation on people having real friends as we put on making sure the people in our programs get their proper medications, on time? What if we actively treated the experience of loneliness rather than treated the bed being made? Even medical literature documents that people's relationships may be more important, in the long run, than any item on the health-care plan. As the poet W.H. Auden put it: "We must love one another or die."

Our Friends Are Those People Who Are Important To Us

According to Bob Perske, "we know a good friendship when we see it -- we don't have to evaluate it for three or four days." Other insights come from sociological research concerning regular friendships. From these sources, we have seen:

*Friends serve different functions in our lives.

Newton (1989) has summarized at least seven different functions between friends, including: (a) information, (b) feedback, (c) assistance in making major life decisions, (d) emotional support, (e) material aid and services, (f) access to others, and (g) companionship. Amongst all our friends, some may fall into certain functions rather than others. Being a friend to a person with a disability may mean being contributed to in patterns of functions different than the patterns with other friendships.

There are many other differences in functions, also. Men lean more toward activity and companionship in defining their friendships; women more frequently say that emotional support is the most important issue. Some research regarding the social relationships of persons with disabilities is based on counting shared activities. However, we also need to understand friendships from the point of view of determining the people who are important to a given individual, who are the people that they consider are the ones who care the most about them, what functions do those individuals serve, whether or not activities are shared.

policy makers and others who influence their lives to listen.

To request a copy of this report, contact: World Institute on Disability, 510 16th Street, Oakland, CA 94612. Tel. (415) 763-4100.

PUBLICATIONS/RESOURCES

Institute on Community Integration. A new publication is available from the Institute on Community Integration, University of Minnesota:

IMPACT: Feature Issue on Family Support--highlights national, state, and local programs that are addressing support services to families.

Contact: Publication Office, Institute on Community Integration, 150 Pillsbury Drive, Southeast, Minneapolis, MN 55455. Tel. (612) 624-4512.

Transition Curriculum Project. The Transition Curriculum Project has produced a number of publications and provides information assistance regarding the transition of students from school to community living. The project is a joint endeavor of the Minnesota Curriculum Services Center and the Interagency Office on Transition Services of the Minnesota Department of Education. Curricula will soon be released regarding: home living; jobs and jobs training; community participation; recreation and leisure; and post-secondary training and education. A number of resources are also available on a loan basis from a lending library. For more information, contact: Transition Curriculum Project, Minnesota Curriculum Services Center, 70 West County Road B-2, Little Canada 55117. Tel. (612) 483-4442, or (800) 652-9024, toll-free in Minnesota only.

TECHNOLOGY CONFERENCE SCHOLARSHIPS ANNOUNCED

The Governor's Advisory Council on Technology for People with Disabilities has announced the availability of a limited number of scholarships for attending the 1990 Closing the Gap Conference. This international conference on microcomputer technology in special education and rehabilitation will be held at the Radisson South Hotel, Bloomington, on October 18-20, 1990. Scholarships

are available to individuals with disabilities, family members, and professionals who are residents of the State of Minnesota. Scholarships include registration fee and a stipend to help defray expenses. To apply, call: (612) 296-2771.

TRAINING FOR PARENT CASE MANAGERS SCHEDULED

Parent case management is the focus of a series on self-determination and empowerment for persons with developmental disabilities. One-day training sessions are intended to enable attenders to participate more fully in the case management process, and will be helpful to parents, guardians, family members, case managers, advocates, and persons with developmental disabilities. Topics covered will include: functional goals, health care, and technology. The 1990 Fall schedule is as follows:

Bemidji Technical College, Bemidji, MN
August 4, 1990, 9:00 a.m. to 4:30 p.m.

Hibbing Technical College, Hibbing, MN
August 4, 1990, 9:00 a.m. to 4:30 p.m.

Marshall Southwest State University, Marshall, MN
August 18, 1990, 9:00 a.m. to 4:30 p.m.

A fee of \$10.00 includes lunch and materials. Contact: Marijo McBride, Institute on Community Integration, 6 Pattee Hall, 150 Pillsbury Drive, Southeast, Minneapolis, MN 55455.

SEMINAR

November 28-30

Early registrations are being accepted for participating in "Job Coach/Employment Specialist Train-the-Trainer Seminar" to be held in St. Cloud. The main speaker will be Eric Rudrud, professor in the Department of Applied Psychology at St. Cloud State University. The seminar is sponsored by the Alliance for Training and Technical Assistance. Contact: Terri Wallace, Institute on Community Integration, University of Minnesota, 6 Pattee Hall, 150 Pillsbury Drive, Southeast, Minneapolis, MN 55455. Tel. (612) 626-7220.

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LENDING LIBRARY SELECTIONS

Nonaversive Intervention for Behavior Problems: A Manual for Home and Community, L. H. Meyer and I. M. Evans, Paul H. Brookes Publishing Company, 1989. This guide attempts to apply the principles and practices of learning and behavior theory to daily living at home, work, and in the community. The major theme of this manual is the design of behavioral programs that do not compromise the individual's lifestyle and dignity. "Services and supports to adults (and children as well) must reflect recognition of these individual's rights to self-determination," the authors state. Content concentrates on approaches to address individualized needs in a variety of formal and informal circumstances. Principles and practices useful in the training of service and support professionals are provided. Blank copies of forms in the manual are provided in the Appendix for duplication and use in individual programs.

The Syracuse Curriculum Revision Manual: A Group Process for Developing a Community-Referenced Curriculum Guide; Roberta Schnorr, Alison Ford, Linda Davern, Seunghee Park-Lee and Luanna Meyer; Paul H. Brookes Publishing Company, 1989. This manual provides a year-long, step-by-step process for developing a local version of its companion book *Community-Referenced Curriculum Guide* (see above). The process was field-tested across 12 school districts in 8 states. This manual emphasizes the importance of determining a district's individual strengths and needs, as well as involving both parents and teachers in curriculum development.

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CALIFORNIANS WITH DEVELOPMENTAL DISABILITIES ASSESS THEIR 'QUALITY OF LIFE'

"The most basic form of empowerment is to listen to a person and take what they have to say seriously," concluded the authors of a newly released report by the World Institute on Disability. The report is entitled *People with Developmental Disabilities Speak Out on Quality of Life: A Statewide Agenda for Enhancing the Quality of Life of People with Disabilities*. The report is a result of a project funded by the Administration on Developmental Disabilities, Office of Human Development Services, Washington, D.C. The purpose of the Quality of Life Project was to speak directly with persons with developmental disabilities and ask them to define for themselves the issues that are significant in their daily lives. The following statements summarize what over 200 individuals attending 6 regional conferences in California had to say about what their lives were like and what it would take to improve their situations in the general areas of work, living, loving, and playing/ recreating.

WORK

As expressed by one person, "Basically we want the same things you want from a job: happiness, more money, doing what we enjoy, working where we want, regular hours, and privacy." Issues discussed included some of the following: a) wages need to be increased so that people can earn enough money to support themselves; b) sheltered employment segregates people with disabilities from the community--job tasks are often boring, repetitive, and are dead end with no opportunity for advancement; c) there is a lack of understanding about benefits and a fear of being penalized by a loss of benefits when earning more money; d) training is needed in all areas of pre-employment; e) technology such as computers and adaptive

equipment are not readily available; f) attitudes prevent a positive self image--persons with

developmental disabilities are often treated as children by parents, employers, and service providers and are not encouraged to take the necessary risks needed to improve the quality of their lives; g) freedom to choose a job is seen as essential to job satisfaction; h) accessible transportation is seen as essential to successful employment; and i) a pleasant working environment is very important to job satisfaction.

Recommendations regarding work included:

1. Self-advocacy groups should be a priority when it comes to funding and policy decisions regarding persons with developmental disabilities. People need to know their rights and responsibilities as workers.
2. Widespread education programs are needed to teach employers, care providers, and the greater community to see the abilities not the disabilities of people.

LIVING

As stated by another self-advocate, "We should have input into any program that is paid to help us. We need to have more control." Quality of life issues related to living/ residences included: a) freedom of choice--choosing one's own lifestyle is the first and most important step in determining the quality of a person's life; b) Overprotection and lack of communication are seen as major obstacles to achieving goals and making independent decisions; c) right to privacy, to come and go without restriction, and to have input into house rules were of utmost importance, but also to share in the responsibilities such as to get along with others and

to participate in household tasks; d) training in independent living is needed in money management, cooking, housekeeping, mobility, communication skills, tenants' rights, self-advocacy, hiring attendants, medical management, and the use and availability of adaptive equipment; e) safety, emergency procedures, and self-protection; f) affordable and accessible housing; g) services which support community participation; h) respect, trust, and understanding from family and friends. Generally, the conference participants felt that they were not treated as adults and afforded the same opportunities for challenge as their nondisabled peers.

Recommendations regarding living included:

1. Increased funding is needed to provide independent living skills training, thereby making it available to all persons regardless of the nature of their disabilities or where they live.
2. Peer counseling should be made available to primary and secondary consumers. The provision of positive role models is essential to empowerment.

LOVING

"We want the same things as you want: marriage, children, meet new friends, live with boyfriend or girlfriend, a honeymoon, adopting children if we can't have our own, to have someone to cook for and take care of, and travel to see family members," one conference attendee summarized. Issues regarding loving and relationships included: a) self-esteem--being able to love yourself, accepting others as they are, trusting, taking criticism, having faith, asking for help, talking with friends about feelings, and being respected and understood by others; b) restrictions on privacy and dating reinforce the message that people with disabilities should not have sexual relationships; c) lack of privacy in residential settings--no opportunities to have partners in their rooms, spend the night away, come and go without permission, have privacy while using the phone, and be able to do what they want in their bedrooms without asking permission; and d) the need for information on pregnancy, adoption, and child rearing so that they can make informed choices about parenting. There was a need to have more relationships of all kinds--most of all, supportive family relationships, as well as more opportunities to meet and make friends.

Recommendations about loving and relationships included:

Services which provide information and counseling on issues related to relationships need to be accessible to persons with disabilities both in terms of programmatic and physical access. Issues identified were sexuality, parenting, adoptions, sexual abuse, and AIDS.

PLAYING/RECREATING

As summarized by one person, "People get in the way of our decision making by making decisions for us instead of letting us speak for ourselves." This was the most common complaint, "People want to make their own decisions on how and with whom to spend their leisure time." There is a need to learn what social activities exist in the community, and how to meet people with similar interests. Public places and programs need to be made fully accessible, such as the need for closed captions on films and adaptive sporting equipment. The lack of accessible transportation on evenings and weekends is a barrier to enjoying a satisfying social life.

Recommendations regarding playing/recreating included:

1. Independent living skills training programs need to teach how to find out what activities are happening in the community, where they are located, and how to get there.
2. Public places and programs need to be made fully accessible.

In summary, the authors concluded,

People with developmental disabilities share a very strong desire to become more involved in their communities at every conceivable level. They want to live more independently, to be perceived and treated as adults, and to have meaningful and well-paying employment. They want to have choices. . . They want the same things as everyone else: they want the support of their families and their community in achieving the goals that they have defined for themselves, and they want to assess for themselves what gives quality to their lives. . . When they speak for themselves, their ideas are cogent, understandable, and clear. The challenge is for

*Frequency of contact is not necessarily a barometer of intensity of relationship.

Many people have "best" friends whom they see rather infrequently, even less than once a year. People whom you see very frequently may not at all be people you care about the most. We often find similar phenomena in working on "relationship maps;" the folks people with disabilities see every day are not necessarily considered the people who care the most. The people they care about the most are often people they have not seen in a long time, or do not see frequently; that doesn't mean that the intimacy, sense of belonging or connectedness, is any less.

*What it is to be a friend is to contribute.

Sometimes, a person with a disability may see someone as a friend, but the other person does not identify the person with the disability as a friend in return. Many individuals with disabilities are contributed to by others; some do and some do not have the opportunity to contribute in return. Many individuals without disabilities do not typically experience being contributed to by people with disabilities. Often, people who have close relationships with people with disabilities experience and recognize contribution in ways that outside observers do not.

Friends Can't Be a "Service"

At the national TASH conference in December 1989 in San Francisco, a parent in one workshop shared about how, after her child graduated from high school, she was put on a waiting list for work services -- a very long waiting list, and then for certain services that were not even connected with a real job. Only because of the commitment of the mother and the work of certain professional friends was the daughter finally able to get a real job. The mother shared passionately about what she wanted for her daughter: "We're not going to go for *services*, we're going to go for *life*."

In our heavily programmed, regulated, and planned delivery of "service," certain danger signals are looming to actually discourage efforts at linking

people with their community members and at having natural, contributory relationships. The human services field is very skilled at establishing requirements, procedures, and processes that discourage natural connection and distance people even further from normal life and normal relationships. Some potential areas of danger include:

- *friends as a goal in an IHP, attached to measurable objectives and completion dates
- *characterizing community connections as a program service

- *the potential of a requirement that community persons have background checks if they do anything with a person who is in a program

- *the potential of subjecting community friends to "program volunteer" status and training requirements

Having friends must exist in a different domain than program features that are measured, objectified, regulated, licensed, monitored, broken down into achievable steps, and are part of the per diem. Staff efforts at connecting people can still be planned and intensified, but must exist in a different context. Friends are a feature of *life*, not service.

Staff Relationships and Roles as Community Connectors

Many commentators on the issue of social relationships of persons with disabilities have noted that frequently, paid staff persons have very significant, meaningful relationships with the persons they serve. For many staff persons, the experience of relationship and caring is very important; many continue to maintain relationships even after they leave a job.

For person working in the field of human services, it has been documented that the factors of low pay and poor skills with the presenting problems contribute to extremely high turnover. However, many staff do stay, even when the pay is low. For staff and agencies, there are the issues of turnover and staff training; for the persons with disabilities, there is the issue that numerous staff dance in and out of their lives, appearing and disappearing. A sense of loneliness and questioning who it is that really cares is quite common.

There is the potential for enormous impact on the quality of the lives of both staff and those receiving

services if we begin to more rigorously address the issue of the sense of relatedness, caring, and direct understanding of the lives of people with disabilities -- in the hiring of staff, in their preservice and inservice training, even in their selection to work in this "field." What if no one could be hired, or enter a preservice training program, until they first had successfully established a friendship with a person with a disability? And what if the criteria for success was that the person with the disability affirmed that the potential staff was significant in their lives and really cared more about them than about being a "service provider" or "professional"?

The issue of staff understanding and willingness to deeply share in the lives of people with disabilities is one issue. A second is that while many staff have significant relationships to the people they work with, they can also take on an additional role. As opposed to being the only or most significant relationships or friendships people have, staff can actively work on the additional role of being connectors to other people.

Instead of just doing programs on skills training or doing physical care-taking, or taking people to "community activities," an additional role can be introducing people, bringing people to places where they meet other people, looking at who among their own friends people can be linked, and informally educating community people. It takes no more time, but rather a shift in thinking, to alter from taking people to community activities (the mall, movies, eating out, etc.) to going places where people can get to know people over time, be appreciated and become friends. It does also take some forethought and support, to have these connecting experiences be successful for both the person with disabilities and the community members. When successfully thought out and supported, we are finding that friendships can and do develop.

"The Community" Is not a Noun but a Verb

For each person, there is not one "community," which exists "out there" (like a thing), to which we build connections. For each of us, our community changes over time and dependent on our interests. If we define community as the people to whom we are connected, then our community today is different than it was a year ago. We move; other people move in and out of our lives. The community changes based on many factors such as

job changes, life transitions and commitment changes.

We will *never* be able to say that we have successfully connected people with disabilities to their community--like something that is complete, finished, achieved. For all of us, being related and being connected goes up and down every single day of our lives. Being connected to others is ever-changing; it follows life. Every day is different. For people we work with, establishing and maintaining friendships will be a challenge till the day they die; our job of supporting will never be over.

WORKSHOPS

July 30

"Sexuality Awareness, Assessment and Training of Persons with Developmental Disabilities" will be held from 9:30 a.m. to 4 p.m. in the staff training room of Thomas Allen, Inc., 1555 Livingston Av., West St. Paul. Jo Jackson, author of the *Woodvale Sexuality Assessment* will be the instructor. The fee is \$40. It will cover establishing a good environment for sexuality education, assessing needs, determining goals, teaching deficit areas, dealing with problems, and more. For more information, call Shirlee Ness at (612) 450-1802

August 5 to 10

"Framework for Accomplishment" is a five-day workshop that provides a valuable learning opportunity for persons who are ready to do something about improving the quality of life for persons with disabilities. It is based on the assumptions that services should support valued membership for all people in a community, that services are likely to distance people from ordinary experiences of community life and that there is no quick fix. It focuses on capacity building and constructive actions. The workshop will be held at the Holiday Inn Shoreview at I-694 and Lexington Av. The fee is \$275. Tuition, written materials, coffee breaks and lunch on Monday and Friday are included. Registration is due by July 20. For a complete brochure or more information, contact Jane Wells, Creative Community Options, 4209 Oakmede Lane, White Bear Lake, MN 55110 or (612) 426-9263.

DD

INFORMATION EXCHANGE

*Published monthly by the Developmental Disabilities Program of the Metropolitan Council
Editor: Kay Zwernik*

Metropolitan Council
Mears Park Centre
230 East Fifth Street
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Vol. 14, No. 8
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VOLUNTEERS NEEDED FOR METROPOLITAN COUNCIL'S DISABILITIES ADVISORY COMMITTEE

The Metropolitan Council is taking applications from Twin Cities Metropolitan Area residents interested in serving on its Disabilities Advisory Committee.

The volunteer committee advises the Council on the needs of people with mental, physical and developmental disabilities and helps coordinate planning to meet those needs.

The 25-member committee is made up of persons who have disabilities, their parents or guardians, service providers and the general public. Members serve three-year terms. There are eight vacancies to be filled.

The committee usually meets the third Tuesday afternoon of every other month. Members are expected to serve on subcommittees. They volunteer their time, but are reimbursed for their expenses such as parking and transportation.

For more information, call Council staff Kay Zwernik at 291-6364. For an application form, call Stephanie Andress at 291-6427. Application

deadline is Sept. 18. Appointments will be made by the Council Sept. 27, and the new terms will begin Oct 1.

The functions of the former Developmental Disabilities Advisory Committee are being expanded to include all disabilities. This change will assist the Metropolitan Council to better plan for the entire disability community.

A NEW DECADE. THE 1990s: BUILDING INCLUSIVE COMMUNITIES

More on Friendships

A Fable for Families: Faith and Doubting Thomas Debate and Define Friendships

One afternoon Doubting Thomas happened upon Faith and, knowing her will, for they were old adversaries, asked, "What causes you to shine so brightly? You are aglow. A good meal, no doubt."

Faith answered, "No, it is my recurring dream, so rooted in my soul that I must share it with even you. I dream about our hearts and spirits. They are needy. They need companions. They can find them only within communities. I want to build communities that connect our hearts and souls."

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Thomas: "More idle thoughts, again! I should have known. What ever comes of them?"

Faith: "Yes, I have a thought. . . a thought of the heart. I dream of a community of peace, where people bearing disabilities will be givers of care rather than only receivers, hosts rather than guests. They will transform their disability into hospitality."

Thomas: "Just how will you create community? What will it do? What will you call it?"

Faith: "I will build it out of our urgent needs for each other. We are all in crisis--the crisis of being cut off from each other. Crises create community. I will call this community 'friendship.' Friendship will have no boundaries; thus, it may welcome all. With it, I will change the lives of all who come to it."

Thomas: "That's a bold statement, heavy on sentiment but light on substance."

Faith: "Wrong! All of us have needs, whether we have disabilities, or are family members, or professionals. If we have disabilities, we need friendships to satisfy our emotional and social needs and to give us real opportunities in life. If we are family members, we need friendships to provide us with support, because professionals and services, though necessary, are not sufficient. If we are professionals, we need friendships to be effective with those we serve, as our technical skills are more powerful if fueled by friendship."

Thomas: "Well, I'll grant you this--you've got substance there. But what is friendship, what are its characteristics? Be specific."

Faith: "Friendships are freely chosen and freely given. Friends take risks for each other; they also take risks by just being themselves."

Thomas: "Fair enough definition. But what good is friendship, especially for people with disabilities and their families?"

Faith: "I answered that when you said I was light on substance. But let me amplify."

"For the person with disability, friendships offer emotional fulfillment. They also create full citizenship--opportunities for the person to have a regular life, with regular friends, jobs, and living

arrangements. Those, not government payments, are the greatest social security.

"It is the same for the family, but friendships also add to the family's resources and strengths. They satisfy the family's needs. The family that builds friendships is cultivating a 'marathon skill.' Friendships help them run the race of life without dropping out.

"For professionals, friendships make their work more effective. Friendships create trust, and trust enables professionals to work with families, just as it helps families help professionals.

"For the ordinary citizen, friendships show the positive contributions of the person with a disability."

Thomas: "I'll pretend that you convinced me, for I want to know this: How do you promote friendships?"

Faith: "One begins with a sense of urgency that causes you to turn from yourself to another, usually to a very ordinary person, who is open and wants a friend.

"A friend tells his or her story, and listens to the other's story. In this way, friends share feelings of joy and pain. Stories are the tissue of friendship. By telling a story, a friend invites the other to share a life, to be hooked on a dream.

"A friend invites the person with a disability to share his or her special gift, to bestow the too-often hidden talents and genius.

"A friend helps the other feel useful and appreciated.

"A friend makes the other feel welcome; there must be occasions for hospitality, room for joy as well as pain.

"A friend vouches for the other and is there when needed.

"A friend shares the stigmas of disability. But a friend also creates opportunities to share respectability.

"A friend self-consciously gives the other a claim on oneself.

"A friend derives energy from seeing the gap between reality and the other's vision.

"A friend is not a 'provider' to the person with a disability. Sure, professionals can be friends. But a 'provider' creates a 'client,' and different status in a relationship does not easily foster friendship. This is because the provider-client status does not regard the essence of the person as the defining characteristic of the relationship."

Thomas: "Let's say I want to help people with disabilities and their families develop friendships. What stands in the way?"

Faith: "I have already told you some of the barriers. They are stigma, clienthood status, and being cut off from each other, which we call segregation. But a major hurdle is lack of courage. Friendship does not flourish in the face of unwillingness to commit, to acquire acceptance by running the risk of rejection. Fortune favors the brave. Another barrier is our vision: we only believe if we can see, but we can only see if we will believe. We much believe in the power of friendship. Then we will see what it can do."

Thomas: "Faith, will you be my friend?"

Faith: "Of course. Your gift was asking questions, inviting me into your life. You ran a risk with me. Now, tell me your story."

The previous article was written by H. Rutherford Turnbull, for the *Families and Disability Newsletter* published by the Beach Center on Families and Disability at the University of Kansas, Lawrence, KS.

FOR YOUR INFORMATION

Housing Loan Program Expands

ARC of Hennepin County recently received permission from the city of Minneapolis to expand the uses of its Community Development Block Grant residential loan account. The ARC now has authorization to make loans for upgrading ICFs/MR from Class A to Class B and to make loans for the establishment of residences under the waiver or Semi-Independent Living Services (SILS) in Minneapolis.

Expenses for which loans could be made include, but

are not necessarily limited to:

- o Costs of physical plant modifications.
- o Expenses related to acquiring the "program" expertise required to address the special needs of residents for whom services have not yet been developed.
- o Costs related to setting up a residence funded under the waiver or with SILS. Examples might include: payment of a security deposit and first month's rent, connection of telephone and utilities, physical adaptations, adaptive equipment, etc.

Loans can be repaid over a maximum of seven years. Ability to repay must be demonstrated and the loan must be secured. Loan amounts may be \$1,000 to \$20,000 and may be made to a provider, organization, an individual resident or a resident's family. The initial request should be in a letter explaining the details for which expenses will be made. Send the request to Brad Smith, ARC of Hennepin County, 2344 Nicollet Av. S., Suite 370, Minneapolis, MN 55404. For more information, call Brad at 874-6650.

Cost-Benefit Study Under Way

The Minnesota Supported Employment Project is currently sponsoring a cost-benefit study on supported employment in Minnesota. The study, which will be completed by next March, is the final major activity funded by the Office of Special Education and Rehabilitation Services (OSERS). The five-year project is a systems change grant to the State of Minnesota.

The purposes of the study are to:

- o Determine the range of cost to provide supports in integrated employment settings to people with severe disabilities;
- o Identify levels and sources of all resources currently used to pay for services in selected geographic areas;
- o Determine the cash and noncash benefits for the individual, community and state when supported employment outcomes are

achieved; and

- o identify the current demand for supported employment services by consumers.

As part of its contract with the state Supported Employment Project (SEP), the Institute on Community Integration at the University of Minnesota is conducting the study. The study is currently developing the format for collecting the data.

Five counties have agencies providing supported employment that are participating as volunteers in the study. They are Dakota, Goodhue, Hennepin, Otter Tail and Rice Counties.

For more information on the study, call Ed Boeve at the Minnesota SEP Office, (612) 296-5629 or 1-800-328-9095.

National Clearinghouse on Family Support and Children's Mental Health

The Research and Training Center on Family Support and Children's Mental Health has launched the first clearinghouse designed to serve families of children with serious emotional disorders as well as professionals, policymakers and other interested persons. The National Clearinghouse on Family Support and Children's Mental Health includes a national toll-free telephone service, a computerized data bank, a series of fact sheets on issues pertaining to children who have emotional disabilities and their families, a state-by-state resource file, and the addition of a family resource coordinator to the Center's staff.

Available fact sheets address the following topics: children's mental, emotional, and behavioral disabilities; resources (books, journals, newsletters and films) addressing children's mental health issues; starting parent/family support groups; financing; early intervention services; and descriptions of specific children's emotional disabilities, including childhood depression, attention deficit hyperactivity disorder, and childhood schizophrenia.

The Clearinghouse hours of operation are 8 a.m. to noon Pacific Time. When staff are not available, callers may leave their names, addresses, telephone numbers and inquiries on an answering machine. The clearinghouse may be reached by telephoning

(800) 628-1696 or by writing the National Clearinghouse on Family Support and Children's Mental Health, Portland State University, P.O. Box 751, Portland, OR 97207-0751

PUBLICATION

Respite Resource Directory Available

The Statewide Respite Providers is an organization founded to share and supply information, discuss issues and concerns, and determine resolutions for issues specific to respite-care providers in Minnesota. Recently it completed its *Respite Directory*. The publication lists statewide respite resources. It is available for a minimal photocopying and postage fee from the Association for Residential Resources in Minnesota (ARRM) by calling (612) 291-1086.

Statewide Respite Providers meets monthly at the ARRM offices in St. Paul. Anyone who would like to be invited to attend meetings and join the organization. Call Pam Argus at (612) 934-2771 or Gerry McInerney at (612) 291-1086 for additional information of the organization and its meetings.

CONFERENCE

August 16-18

"Individuals First" is the title of a symposium dedicated to issues relating to individuals with developmental disabilities sponsored by the Developmental Center at Grafton, N. D. It will provide opportunities for education, training, and resource networking by having people join together to share knowledge and learn new, innovative strategies to best meet the needs of children and adults with developmental disabilities. More than 50 workshops will be offered in the following four tracks: Life Skills, Health and Wellness, Parents and Providers, and Technology. The registration fees are \$95 for professionals, \$65 for direct-contact staff and students, and \$50 for parents and guardians. The symposium will be held at the Developmental Center, Grafton, N.D. and Memorial Union at the University of North Dakota, Grand Forks, N.D. For further information, contact Jo Coutts, University of North Dakota, Box 8277, University Station, Grand Forks, ND 58202. (701) 777-2663

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Roger Strand, *Editor*
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SERVICE SYSTEMS BUILD ON PEOPLE'S DEFICIENCIES; COMMUNITIES ON THEIR CAPACITIES

The following is a story by John McKnight, which appeared in an article, "Why 'Servanthood' Is Bad," *The Other Side* (January/February, 1989). McKnight is on the staff of the Urban Affairs Center of Northwestern University, and is known for his efforts as a community organizer. In the article, McKnight stated, "Service systems teach people that their value lies in their deficiencies. They are built on 'inadequacies' called illiteracy, visual deficit, and teenage pregnancy." On the other hand, McKnight pointed out that communities are built on the capacities of people.

'HEY JOE, WHAT'S HAPPENING?'

I met a remarkable woman in a little town in southern Georgia. She worked for a service agency responsible for people with mental retardation in a three-county area. Her agency decided it was too focused on deficiencies and needed to think about the gifts, contributions, and capacities of the people who were its charges.

So this woman began spending time with the people the agency had once called 'clients' to see if she could understand what gifts they had. She went to the home of a forty-two-year-old man, Joe. He has one short leg (at least he limps), and he doesn't speak the way a lot of people speak. (I'm not sure what label deficiency-finding psychologists would give him. But I'm sure they would give him one.)

At age twenty-one, Joe had no place in society. So he went home to a pig farm. Every day he did two things. He fed the pigs twice a day, and he sat in the living room where he listened to the radio. (He couldn't see to watch television.)

The woman told me that after four days at Joe's

house she couldn't find his gift. "But on the fifth day," she said, "I realized what his gift was: he listens to the radio."

"I found that three people in town spend all their time listening to the radio, and they get paid for it. One in the sheriff's office, one in the police department, and one in the civil-defense office. So I looked at each of these places where a person sits, listening to a radio all day. I liked the civil-defense office best. It's a voluntary organization. They have a house that somebody gave them; so the voluntary ambulance people sleep in its bedrooms. There's a desk and sitting right by the desk is a radio getting all the calls from the country. At the desk sits a twenty-seven-year-old woman who listens for calls and dispatches volunteers when someone needs an ambulance."

So she told the dispatcher, "I have somebody here who likes to listen to the radio as much as you do. I'd like to introduce you to him." So she introduced Joe to her, and they put a chair on the other side of the desk, and he sat there every day listening to the radio.

This little house is also the neighborhood community center. Somebody is always there. People come and talk and drink coffee in the dining room. Sometimes they show movies. Whenever anybody was there, Joe would go in. Everybody came to know Joe and he became a part of that neighborhood. When Christmas came, the volunteers gave Joe a radio of his own to listen to at home in the evening because Joe had been with them and had shared his gifts in the face of their hospitality.

Joe began to go downtown at noon to eat at the diner. One day he went into the diner and the owner of the diner said, "Hey, Joe, what's happening?" Joe looked at him and said, "The

Smith house over in Boonesville burned down this morning. And out on Route 90, at the turnoff where you can have picnics, there was a drug bust. And Mr. Schiller over in Athens had a heart attack." Everybody in the diner stopped talking and looked around at Joe. They couldn't believe it. They realized that Joe knew the answer to the question, "What's happening?" because he listened to the radio all morning.

When I went to visit this town and the woman who introduced Joe's gift of listening to the radio to the community, I saw an incredible thing. I saw, first of all, that the dispatcher and Joe were in love with each other. Then when I went with Joe to lunch, I saw that everybody who came into the diner came over to Joe first and asked, "Joe, what's happening?" And I realized that I was in the only town in the United States that now has the gift of a town crier.

The woman told me she was planning to take Joe over to the newspaper editor. It had occurred to her that in this little town with a little newspaper and one editor, the editor couldn't possibly know "what's happening." But by noon Joe knew. And if Joe would go over and talk to the editor every noon, the grasp, the breadth, the knowledge, of the newspaper and what it could report would expand mightily.

So Joe is now a stringer for the local *Gazette*. He showers his gifts on the community because somebody knew that community is about capacities, contributions, and hospitalities--not about deficiencies, needs, and services.

COMMUNITY SUPPORT NETWORKS NOW AVAILABLE FOR PERSONS WITH SEVERE HEAD INJURIES

The Minnesota Head Injury Association has developed a Community Support Network Program. Every year approximately 10,000 Minnesotans sustain a head injury. Of that number, nearly 1,000 people develop severe and permanent disability. Most survivors experience deficits in short term memory and the ability to process the subtle signals necessary for daily activities. Other capacities often lost or compromised include fine physical movements, clarity of speech, planning, and judgement. Support networks ensure a positive transition for survivors and their families. Assistance

with personal goals and plans may include employment, training, independent living, housing, recreation, counseling, and transportation. This program was made possible through a grant from the federal Department of Education and the Minnesota Division of Rehabilitation Services. For more information, contact: Minnesota Head Injury Association, 1313 First Street, Southeast, Minneapolis, MN 55414. Tel. (612) 379-3911.

PUBLICATIONS/RESOURCES

AIDS and Persons with Developmental Disabilities: The Legal Perspective, American Bar Association (ABA), 1990. This report discusses federal and state laws which define the rights and responsibilities of individuals with disabilities and service providers, explains how these laws apply to children and adults with HIV infection, and provides policymakers with information for rational policymaking. Five chapters include: antidiscrimination statutes; HIV testing, medical treatment, and informed consent; confidentiality and provider liability; isolation and involuntary civil commitment; and federal benefit and entitlement programs. Topics cover health care, child welfare services, day care and education, housing and residential facilities, vocational training, and employment. An overview is provided of HIV infection, a glossary, and a bibliography. Cost is \$18.00 payable to ABA/FJE. Send orders to ABA, AIDS/DD Project, 1800 M Street, Northwest, Washington, D.C. 20036. Tel. (202) 331-2282.

Social Support Manual, J. S. Newton, Neighborhood Living Project, University of Oregon, 1989. This manual provides strategies, procedures, and tools for improving the social life of persons living in community residential programs. A basic philosophy is that the ultimate success of a residential program can be determined by examining the quality of life of the program's participants. It is about community, commitment, and how to foster friendships. Helpful forms, administrative procedures, and resources are contained in the Appendices. Contact: Neighborhood Living Project; Specialized Training Program, 135 College of Education, University of Oregon, Eugene, Oregon 97403-5215. Tel. (503) 686-5311.

Common Ground: A Celebration of Diversity is a new newsletter published by Communitas, Inc., an international non-profit organization which facilitates the inclusion of all people into community life. To

become a member and to receive the newsletter, simply share your personal vision of community and inclusion of people with disabilities, and highlight personal gifts, experiences, and philosophical direction. Send your request for application/subscription to Communitas, Inc., Box 374, Manchester, CT 06040.

Community Living for Adults is a new news bulletin published by the Center on Human Policy, Syracuse University. Its focus is on new approaches that will support people with severe disabilities in homes of their own. Copies are 85 cents each. A free list of Resources and Reports on Community Integration is also available from the Center on Human Policy, Syracuse University, 200 Huntington Hall, Second Floor, Syracuse, NY 13244-2340. Tel. (315) 443-3851.

Rare Disease Information Resources. An estimated 5,000 medical conditions that affect fewer than 200,000 people in the United States have what is defined as a "rare disease" in the Orphan Drug Act of 1983. At least two organizations provide information about these conditions and resources for assistance: (1) National Information Center for Orphan Drugs and Rare Diseases (NICODARD)--call toll-free (800) 999-6673, or write the center at P.O. Box 1133, Washington, D.C. 20013-1133; and (2) National Organization for Rare Disorders--call toll-free (800) 999-6673, or (202) 746-6518, or write NORD, P.O. Box 8923, New Fairfield, CT 06812.

CYDLINE Reviews. Substance Use by Youth with Disabilities and Chronic Illnesses, National Center for Youth with Disabilities (May 1990). This is one among a series of annotated bibliographies of the National Center for Youth with Disabilities (NCYD), University of Minnesota. The information is drawn from a computerized database of the Center's Resource Library. Literature related to substance abuse is organized by specific disabilities such as: mental retardation, learning disabilities, mental illness, sensory disabilities, other physical disabilities, chronic illnesses, and multiple disabilities. Suggested training materials are listed. In addition, a helpful checklist is provided for the selection of treatment programs.

Other topics in the series include: transition from pediatric to adult health care, issues related to chronic illness for school personnel, decision-making,

and general issues for professionals, youth, and parents. Contact: NCYD, Box 721 University of Minnesota Hospital and Clinic, Harvard Street at East River Road, Minneapolis, MN 55455. Tel. (612) 625-2825 or, 1 (800) 333-6293, toll free.

Publications Catalog, 1990, Beach Center on Families and Disability, The University of Kansas. This catalog lists publications based on research with families of persons with disabilities. The Beach Center is a research and training center with six fundamental beliefs about families. These beliefs are rooted in positive contributions, great expectations, full citizenship, choices, strengths, and relationships. A wide range of topics address family well-being, such as: adolescent health, adults with disabilities, children with technology support, choices and preferences, disability law, family coping, family diversity, family-professional relationships, research, family support, parent to parent, permanency planning, supported employment, and transition to adulthood. Contact: Beach Center on Families and Disability, The University of Kansas, Bureau of Child Research, 4138 Haworth Hall, Lawrence, Kansas 66045. Tel. (913) 864-7600.

EVENTS

August 17

Help celebrate the passage of the Americans with Disabilities Act. A party will be held from 3:00 p.m. to 6:00 p.m. at the Minneapolis Convention Center. The feature program will start at 4:00 p.m. For more information, contact: Wendy Brower, Minnesota Multiple Sclerosis Society, Tel. (612) 870-1500, or (800) 582-5296 (toll-free, voice and TDD).

August 17-18

"USHERing in the 1990s" is a workshop on Usher Syndrome (deafness and retinitis pigmentosa) for consumers, families, and professionals. The workshop will be held at the Omni Northstar Hotel in Minneapolis. Keynoters include: Lea Hyvarinen, Ophthalmologist, University of Helsinki, Finland; and McKay Vernon, Psychologist, Western Maryland College. Contact: In Touch, Inc., 1111-Third Avenue, South, Suite 30, Minneapolis, MN 55409.

The State Developmental Disabilities (DD) Program Office has acquired several education, training and resource materials. The following materials may be borrowed from the State Office only, located at the address on the front sheet of the State Supplement section of this newsletter. Tel. (612)296-4018.

LENDING LIBRARY SELECTIONS

The following videotapes (VHS, 1/2 inch) are now available on a two-week loan basis:

Starting Over: Life After a Severe Head Injury, produced by North Carolina Council on Developmental Disabilities, is intended to help people to understand the nature and effects of severe head injuries. It also illustrates appropriate methods and techniques for assisting the individual with a severe head injury to transfer skills learned in rehabilitation settings to their homes.

You Can Vote, Michigan League of Women Voters and the Michigan Developmental Disabilities Council, encourages people with disabilities to meet their responsibilities as citizens--to register, and to vote.

Assistive Technology: A Mother's Perspective, United Cerebral Palsy Associations, a presentation at a national conference by a mother, who tells about the significance of assistive technology in the life of her son who has cerebral palsy.

Case Management: Historical, Current, and Future Perspectives, M. H. Linz, P. McAnally, and C. Wieck (Eds.), Brookline Books, 1989. As noted by R. Bruininks (University of Minnesota), "This book contains essential material and concepts for addressing the role of case management in the many and varied challenges of providing full opportunity for citizens with disabilities in our homes, schools, and communities." This volume contains presentations given at a Minnesota conference on case management in 1986, co-sponsored by the Minnesota University Affiliated Program for Persons with Developmental Disabilities and the Minnesota Department of Human Services. Additional chapters are contributed by invited experts. Both personnel and parents in the field of case management discuss practices that have evolved through recent history, what is currently being provided, and possible future trends. As noted by Wieck, "Case managers are absolutely critical to the conversion from traditional services to community integration." Contributing authors include: Allan Bergman, Luther Granquist, Dorothy Kerzner Lipsky, Marijo McBride, Robert McDonald, John McKnight, Betty Pender, Carla Peterson, Edward Skarnulis, Lyle Wray, and Thomas Zirpoli. Available on a three-week loan basis, or may be purchased for \$24.95, payable to: Brookline Books, Inc. P.O. Box 1046, Cambridge, MA 02238-1046.

Metropolitan Council DD Program
Mears Park Centre
230 East Fifth Street
St. Paul, MN 55101

If you no longer wish to receive this newsletter, please call (612) 291-6364, or write to the DD Program, Metropolitan Council Mears Park Centre, 230 East Fifth Street, St. Paul, MN 55101

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Editor: Kay Zwernik*

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Vol. 14, No. 9
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METROPOLITAN COUNCIL TO CEASE PUBLICATION OF DD INFORMATION EXCHANGE

This is the last issue of the *DD Information Exchange* to be published by the Metropolitan Council. The newsletter, begun by Toni Lippert, has been published by the DD Program of the Metropolitan Council since 1974. In the 15 years of its existence the readership has grown from a couple hundred to about 3,300 people and agencies. The mailing list includes people from around the United States and Canada and several foreign countries. Many positive and enthusiastic verbal and written comments have been received about the content of the newsletter from throughout Minnesota and around the country.

The *DD Information Exchange* was initially published by the Region XI Developmental Disabilities Task Force of the Metropolitan Health Board. In 1983, the Governor's Planning Council on Developmental Disabilities, which is part of the State Planning Agency, joined with the Metropolitan Council to publish the *State Supplement*. In the years that followed, the monthly publication has been a joint effort between the Metropolitan Council and the Governor's Council. Roger Strand has been the editor of the *State Supplement* and Kay Zwernik

has, since 1988, been editor of the *DD Information Exchange*. The Metropolitan Council has decided that it no longer wishes to allocate staff and dollar resources to the publication of the newsletter.

The *DD Information Exchange* and the *State Supplement* have endeavored to bring their readers policy issues, stories about people and their contributions to their communities, conference summaries, abstracts of new publications, announcements of various training events, items of general interest, job openings and items in keeping with current best practices in the field of developmental disabilities. Roger and Kay thank you, our loyal readers, for your support.

"The joint participation with, and the contributions of, the Metropolitan Council to publish this newsletter will be greatly missed," said Colleen Wieck, Executive Director of the Governor's Planning Council. The Governor's Planning Council plans to continue to publish a monthly newsletter and will continue to use the same mailing list. Readers should send ideas for future articles to Roger Strand, Governor's Planning Council on Developmental Disabilities, 300 Centennial Building, 658 Cedar St., St. Paul, MN 55155.

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VOLUNTEERS NEEDED FOR

METROPOLITAN COUNCIL'S DISABILITIES ADVISORY COMMITTEE

The Metropolitan Council is taking applications from Twin Cities Metropolitan Area residents interested in serving on its Disabilities Advisory Committee.

The volunteer committee advises the Council on the needs of people with mental, physical and developmental disabilities and helps coordinate planning to meet those needs.

The 25-member committee is made up of persons who have disabilities, their parents or guardians, service providers and the general public. Members serve three-year terms. There are eight vacancies to be filled.

The committee usually meets the third Tuesday afternoon of every other month. Members are expected to serve on a subcommittee. They volunteer their time, but are reimbursed for their expenses such as child care, parking and mileage.

For more information, call Council staff Kay Zwernik at 291-6364. For an application packet, call Stephanie Andress at 291-6427. Application deadline is Sept. 18. Appointments will be made by the Council Sept. 27, and the new terms will begin Oct. 1.

The functions of the former Developmental Disabilities Advisory Committee are being expanded to include all disabilities. This change will help the Metropolitan Council plan better for the entire disability community.

A NEW DECADE: THE 1990s BUILDING INCLUSIVE COMMUNITIES

How to: Build Friendships

Tips for Families

1. Confront negative attitudes directly by providing information through a personal story, fact sheet, or public relations program through the neighborhood school or support group.

2. Realize that others may want to give you a

hand, but are too shy to offer. Take the risk and respond to tentative offers to help with specific suggestions. Be assertive and ask a friend or acquaintance for help, such as picking up a few groceries or watching your children while you go to the laundromat or take a sick child to the doctor.

3. Listen to others' problems. A friendship is a reciprocal relationship and you have valuable coping and "marathon" skills to share. Listening to friends' stories is important.

4. Create friendships through a base of common experiences. Force yourself to voyage out into your community and socialize. Summer softball leagues, local museums, or churches or synagogues are inexpensive options which can include the entire family.

5. Refuse to let differences threaten your friendships; take the first step to talk it out, and try to see the situation from the perspective of the other person. Friendship is too important to lose over a conflict which may seem insurmountable today, but minor a month from today.

Tips for Professionals

1. Listen and affirm what you hear.

2. Share some of yourself. Make sure you do this at the appropriate times--not when someone needs you to listen.

3. Respect family members' opinions about their children, taking action on their requests to the greatest extent possible. If it is not possible, explain why.

4. Understand that your values, cultural background, and attitudes will affect your interactions with family members. Knowing yourself will help you appreciate differences in others, instead of fighting against them.

5. Recognize that the development of respect and trust takes time.

6. Communicate with family members in their primary language, whenever possible.

The previous article appeared in the *Families and Disability Newsletter* published by the Beach Center

on Families and Disability at the University of Kansas, Lawrence, KS.

EMPLOYMENT CENTER TO BE TOTALLY COMMUNITY BASED

On Aug. 23 of this year, Kaposia, Inc, a St. Paul-based employment service for persons with developmental disabilities, closed the doors on its last segregated facility. Services to Kaposia's 125 workers now will all be provided in integrated community settings.

Kaposia, Inc., in its 27th year of operation, was a traditional developmental achievement center providing functional skill training, recreation and leisure activities, and pre-vocations skill training to 65 adults in segregated settings until January 1984. At that time the board and staff made a commitment to become a "service without walls" by providing jobs to people through supported employment, a concept designed to support persons previously excluded from community employment because of severe disabilities.

Individuals served by Kaposia receive support in career planning, job placement, initial on-the-job skill training and whatever ongoing supports are necessary to maintain job retention and satisfaction. This has allowed individuals with disabilities the opportunity to work in socially integrated settings, dramatically increase their earnings and benefits, develop friendships with a variety of co-workers who are not disabled and develop a sense of pride and self-esteem. Supported employment has also provided local employers with a source of dependable, productive workers who can help meet the rising demand for entry-level labor at a time when the numbers of young people who have traditionally filled those positions are declining.

Kaposia, Inc., has been recognized several times over the past six years for its efforts in promoting supported employment strategies. In June 1986, Kaposia received an Outstanding Community Service Award from the Minnesota Department of Human Services and also recognition from Syracuse University as a national model for socially integrating persons with severe disabilities. In 1989 Kaposia was presented with the Walter and Lydia Duebner Award from the St. Paul Area Chamber of Commerce for Small Business Innovation and Entrepreneurship in the nonprofit sector. Also in

1989 Kaposia was recognized by the Southwest Regional Rehabilitation Exchange in Austin, Texas a nation model of supported employment.

FOR YOUR INFORMATION

Disability Employment Awareness Month

October is National Disability Employment Awareness Month. The President's Committee on Employment of People with Disabilities has selected a theme, "Employment: Investing in America's Future," and has prepared a publicity campaign packet. To obtain a copy of the packet and for more information, contact: The President's Committee on Employment of People with Disabilities, 111-20th St., Suite 636, Washington, D. C., 20036. Tel. (202) 653-5044.

Referral and Placement Service Available

The Johnson and Associates Consulting Group is a personnel consulting firm that provides temporary medical and human service staff in programs that serve individuals with developmental disabilities. Such programs would include group homes, day training and habilitation programs, and supported employment programs. Johnson and Associates maintains the standards and requirements of the requesting agency by screening and placing only highly qualified staff. Examples of available positions include behavior analyst, case manager, director, job coach, residential assistant, counselor, community trainer, licensed psychologist, nurse and practical nurse. Human service agencies experiencing difficulty filling positions or experiencing high turnover may find the service beneficial. For further information, contact Dana Johnson, Johnson and Associates Consulting Group, 1396 White Bear Av., St. Paul, MN 55106 or call (612) 774-5843.

Computer Aided Design Training Program

The Computer Aided Design (CAD) training program began its first class on June 18, 1990, with 17 students. Students attend the nine-month course at the Minneapolis Rehabilitation Center at 1900 Chicago Av. S., Minneapolis, Minn.

CAD is computerized drafting. Traditional drafting and design that was done with the use of a drafting formerly completed with the use of a drafting table,

pen and ruleris now being replaced by computers and specialized software. The use of computers results in a quicker, more accurate and versatile design.

The goal of the CAD program is to successfully train individuals who have severe physical and/or sensory impairments and place them into professional computer drafting positions. The CAD programs is a cooperative venture between the Minneapolis Rehabilitation Center, the Minneapolis Community College, Minnesota Division of Rehabilitation Services, Thief River Falls Technical College, IBM Corporation, Minnesota Job Skills Partnership, and a Business Advisory Council of prominent Twin Cities businesses.

The next class will begin in January 1991. For further information about the program and registration, contact Patrick Sheehan at (612) 879-5422 or John Holmes at (612) 879-5434 or 879-5519 TDD).

Program Now Available to Jewish Adults with Developmental Disabilities

Jewish Family and Children's Service of Minneapolis has been funded by Minneapolis Jewish Group Homes, Inc., for one year to begin a pilot program to serve adults with developmental disabilities and their families. Services to be provided will include direct outreach and support; professional evaluation of each person's needs; goal planning; case management; and development of individualized independent living skills programs. The program will also seek to educate the community about the needs of people with developmental disabilities, the stigmas and obstacles people face in their daily lives, and the role the community can play in supporting them to function as independently as possible. It has been estimated that approximately 250 Jewish adults have developmental disabilities in the Twin Cities. For further information about this program, contact Marci Alexander, Jewish Family and Children's Services, 1500 S. Lilac Drive, Minneapolis, MN 55416; or (612) 546-0616.

National Clearinghouse on Family Support and Children's Mental Health

The Research and Training Center on Family Support and Children's Mental Health has launched the first clearinghouse designed to serve families of

children with serious emotional disorders as well as professionals, policymakers and other interested persons. The National Clearinghouse on Family Support and Children's Mental Health includes a national toll-free telephone service, a computerized data bank, a series of fact sheets on issues pertaining to children who have emotional disabilities and their families, a state-by-state resource file, and the addition of a family resource coordinator to the center's staff.

Available fact sheets address the following topics: children's mental, emotional and behavioral disabilities; resources (books, journals, newsletters and films) addressing children's mental health issues; starting parent/family support groups; financing; early intervention services; and descriptions of specific children's emotional disabilities including childhood depression, attention-deficit hyperactivity disorder, and childhood schizophrenia.

The clearinghouse hours of operation are 8 a.m. to noon Pacific Time. When staff are not available, callers may leave their names, addresses, telephone numbers and inquiries on an answering machine. The clearinghouse may be reached by telephoning (800) 628-1696 or by writing the National Clearinghouse on Family Support and Children's Mental Health, Portland State University, P.O. Box 751, Portland, OR 97207-0751.

RECREATION

Juke Box Saturday Night Dance

A Metro-wide dance for adults with developmental disabilities and their families and friends will be held on Saturday, Oct. 20, from 7 to 10 p.m. at the Richfield Community Center, 7000 Nicollet Av. S., in Richfield. The building is totally accessible and located on MTC Route 18 South. The event is sponsored by TRAIL (Transportation Resource to Aid Independent Living). The dance will feature the KDWB Party Music Machine and door prizes. Entry fee is \$5 per person. Bingo and refreshments will also be available. Proceeds from the Dance will go to provide transportation to educational and recreational programs for adults with developmental disabilities who live on their own in Richfield, Bloomington, Eden Prairie and Edina. For further information, contact Elaine Becker at (612) 835-4736 or Nancy Booker at (612) 835-1760.

Trips and Retreats Offered

Eden Wood, a program of ARC of Hennepin County, is sponsoring a variety of excursions. They range from three-day hotel weekends to a week-long cruise on the Caribbean. Participants must be 18 years of age; staffing and fees are based on a 1:3 ratio for individuals who are ambulatory and have no major medical or behavioral concerns. Eden Wood will work with families to accommodate special needs. For further information, contact Eden Wood Camping and Retreat Center, 6350 Indian Chief Road, Eden Prairie, MN 55344. (612) 934-2771.

CONFERENCES/WORKSHOPS

September 10-11

The 1990 National Conference on Dual Diagnosis will focus on *"The Community Integration of Persons Labeled as Dually Diagnosed: Issues and Models."* It will be held at the Clarion Hotel in Cincinnati, Ohio. Nationally recognized speakers will address the conference, which will cover a broad range of topics through keynotes and break-out sessions. Conference fee is \$125. For further information, contact the University Affiliated Cincinnati Center for Developmental Disorders, Pavilion Building, Room 2-57, Cincinnati, OH 45229.

September 12, 19 or October 10, 17

The Twin Cities Society for Children and Adults with Autism, Inc., (TCSAC) is offering its *Introduction to Autism* program in two separate sessions. The "Overview" covers basic information about autism and information and exercises related to working with persons with autism. Individuals may attend either Sept. 12 or Oct 10. The "Communication" sessions provide information and exercises related to understanding communication skills. Individuals may attend on Sept. 19 or Oct. 17. Sessions begin at 7 p.m. at the TCSAC office at 253 E. Fourth St., St. Paul. The fee is \$10. For further information, contact Nancy Kobilka at (612) 228-9074 or Bill Funari at (612) 439-6247.

September 17-18

The Minnesota Association for Guardianship and Conservatorship is sponsoring its second annual conference at the Saint Paul Hotel. It is titled, *"The MAGiC Looking Glass: Visions of the Future."* The

conference will feature the Honorable J. Jerome Plunkett, Honorable Sandra Gardebring, and Arthur Caplan, Center for Biomedical Ethics, as well as 28 concurrent workshops. The fee is \$85 for members and \$110 for nonmembers. For further information, contact Cathy Plessner, Conference Planner, 2038 Summit Av. St. Paul, MN 55105. (612) 698-2006.

September 21

The Minnesota State Chapter of the American Association on Mental Retardation is sponsoring an all-day workshop featuring Lou Brown, Ph.D., professor in the Department of Rehabilitation Psychology and Special Education at the University of Wisconsin. Dr Brown, who has long been known as a visionary and advocate for the rights of people with disabilities, will speak on *"Preparing Individuals with Severe Intellectual Disabilities to Live, Work, and Play in Integrated Environments."* The event will be held at the Drover's Inn, 701 S. Concord, South St. Paul. Registration begins at 8:30 a.m. The fee is \$35 for members and \$45 for nonmembers. Scholarships are available. For registration information, contact Marianne Reich at ARC Suburban, 14451 County Road 11, Burnsville, MN 55337. (612) 431-3700.

September 20, 27 and October 4

Ann and Rud Turnbull, co-directors of the Beach Center on Families and Disability, will lead three live interactive sessions from 6:30 to 8 p.m. on a teleworkshop titled, *"Is There Life After High School for Students with Moderate and Severe Disabilities?: Great Expectations and Best Practices."* The Turnbulls are parents of a 23-year-old son with a severe disability as well as professionals in special education and advocates promoting integration, productivity and independence. Session one will cover great expectations for adolescents and young adults with severe disabilities. Session two will cover best practices in high school programs for achieving great expectations. Session three will cover best practices in supported employment. For live participation in the teleworkshop, sites need a satellite dish (C-band), a television monitor and a telephone. The teleworkshop price for all three sessions is \$250 per site. Satellite sites for teleconferencing can often be arranged through a school district, media center or business. For more information, contact the University of Kansas, Star Schools, Bailey Hall Annex, Lawrence, KS 66045.

September 29

The International Rett Syndrome Association is sponsoring a one-day workshop at the College of St. Thomas, 2115 Summit Av., St. Paul, titled, "*Understanding the Young Woman with Rett Syndrome.*" The target audience is parents, friends, physicians, nurses, therapists and educators. Speakers will include Kathy Hunter, president of International Rett Syndrome Association, Dr. Terri Vandercook, Sharon Sinclair and Dr. Kathryn Green. The conference fee is \$40 or \$60 for couples. Rett Syndrome is a neurological disorder which to date has occurred only in females. Development is normal until at least six months and is followed by a regression that leads to severe physical disabilities and mental retardation. At the present time there is no known cause, treatment or cure. For more information on the conference contact, evenings Diane Kastner at (612) 291-7258 or Mary Timmerman at (612) 483-3189.

October 2

The Minnesota Adult Protection Coalition (MAPC) will convene its first-ever community problem-solving forum on adult protection. The forum, "*Adults in Need of Protection: Strengthening System Response,*" coincides with the tenth anniversary of the Minnesota Vulnerable Adults Act. Keynoting the forum will be Dr. James Bergman, attorney and executive director of Healthways Foundation in Iselin, New Jersey. He has written extensively about abuse, neglect and protective services issues and helped develop protective services legislation. The forum will be held at the Holiday Inn Metrodome, 1500 Washington Av., Minneapolis, MN. The registration fee is \$20 and includes breaks, lunch and materials. For more information, contact Barry Woodward, Hennepin County Adult Protection, at (612) 348-2321.

October 4-5

"*The Creative Options II--for People with the Most Severe Disabilities,*" back by popular demand, will be held at the Minneapolis Marriot Minnetonka, 5801 Opus Pkwy. in Minnetonka, MN. The second annual training symposium will feature nationally known experts in the field of developmental

disabilities. Included are Wade Hitzing, Dana Henning, David Hagner, Fredda Brown, Hope Leet Dittmeier, Patricia Juhrs, Donna Lehr, Marion Stroud, Bruce Uditsky, Rose Galati and Colleen Wieck. Topics will include supporting persons with challenging behaviors; emotional needs of people with challenging behaviors; creating support services for individuals with dual diagnoses; vocational options; care and habilitation for people with complex health needs; meaningful retirement for senior citizens who are severely disabled; developing respectful behavioral approaches; and more. The symposium is sponsored by Minnesota Habilitation Coalition, Region X Developmental Service Providers, Albert Lea Technical College, and Institute on Community Integration. The registration fee is \$96. If four or more attend from any one organization, the fee is \$89 per person. For more information, contact Jeannie Snyder at (507) 373-6064.

October 18 or 23

"Estate Planning for People with Disabilities" will help families develop a comprehensive plan, prepare wills, implement special needs trusts. It will be presented by Estate Planning for the Disabled, Inc. There is no fee. On the 18th it will be held 7 to 9 p.m. at Marquette Bank, 16817 Duluth Av. S.E., Prior Lake, and on the 23rd from 6:30 to 8:30 p.m. at Washington County Library, 2150 Radio Dr., Woodbury.

November 17

ARC Suburban and the ARC Minnesota Education Committee are sponsoring a workshop on "Exploring Education Funding." A panel of individuals from various state agencies, the legislature and advocacy organizations will provide an overview of funding patterns and issues into the 1990s. Tim Moriarty will be the facilitator. The workshop will go from 9 a.m. to 3 p.m. at the United Way Multi-Service Center, 14451 Co. Rd. 11, Burnsville, MN. The fee is \$6 and includes lunch. For information on this workshop or the estate planning workshop, call Jean Bergal Folger at (612) 431-3700. Scholarships are available.

INFORMATION EXCHANGE

STATE
SUPPLEMENT
September 1990

Developmental Disabilities Council
300 Centennial Office Building
658 Cedar Street
St. Paul, Minnesota 55155

Minnesota State Planning Agency
Roger Strand, *Editor*
(612) 296-4018

EMPOWERMENT

The following article appeared in *News* (Summer 1990) of the Association for Retarded Citizens of Oregon, which was adapted from an article appearing in *Networking*, a Bulletin on *Networking, a Bulletin on Empowerment and Family Support*, Cornell University, Ithaca, New York.

It is often said that it is only through the empowerment of individuals and families that social change will take place which will enable people with developmental disabilities to take part in life in the community on an equal footing with everyone else in society. But what is empowerment? According to the Cornell Empowerment Group of Cornell University, empowerment is "an intentional, ongoing process centered in the local community, involving mutual respect, critical reflection, caring, and group participation, through which people who are lacking in an equal share of valued resources gain greater access to and control over those resources."

An Ongoing Process

By defining empowerment as a process, we are distinguishing it from outcomes, while recognizing that changes in individuals, networks, groups, and institutions contribute to the process. Ongoing means evolving and recurring. Outcomes produced, therefore, generally lead to further participation in the process.

Centered in the Local Community

The energy for empowerment does not come from the government. Neither does it come solely from individuals, families, or networks. Individuals, families, networks, and government all working together, interacting at the local community level, are what give the empowerment process its energy. The process can be facilitated or enhanced at the regional, state, or national level, by the removal of barriers to participation or the provision of

incentives, but the process through which control over resources actually shifts in favor of less advantaged groups of people must take place in the local community.

Mutual Respect

This means that all people have strengths, that diversity is positively valued, that people without power have as much capacity as the powerful to assess their own needs, that relations between groups in communities should be organized to provide an equal balance of power and that those who currently do not have the power must play the primary role in developing the strategies by which they gain increased control over valued resources.

Critical Reflection

This is an ongoing effort to assess current life circumstances in light of history and to plan future action based on this analysis. An important part of this reflection is understanding the history which led to a group's not having its share of power. Action then leads again to critical analysis of the consequences of the action, and so on.

Caring

The empowerment process must generate an increased investment in caring and mutual support among participants in the process and in the community as a whole. In the empowerment process, caring is as important as fairness.

Group Participation

Empowerment is more than one-to-one interaction. An essential part of the process is positive validation of the individual by others who are in similar circumstances. Group participation also necessitates

the subordination of individual interests to the needs of the whole, the expanded knowledge base that comes from involving more people and the greater action potential produced by mutual support.

Lacking an Equal Share of Resources

The empowerment process is made necessary by the existence of gross inequities in the distribution of resources in society. This inequity is manifested in political and social organizations at all levels of society. The definition of empowerment explicitly acknowledges the difficulty this inequity has created by identifying those with fewer resources and recognizing the central role that they must play in reducing the inequity. It is the need to find ways to redress this inequity that distinguishes empowerment from individual development.

Greater Control over Resources

Power consists of the capacity to exert control over resources. Thus, the shifting of that control means a shift in the balance of power. By valued resources, we might mean political power, purchasing power, information, social support, education and social status.

FIND, INC. RECEIVES GRANT TO ASSIST PERSONS WITH DEAF-BLINDNESS

Functional Independence Training (FIND), Inc. of Minneapolis has been awarded a grant from the Deaf Services Division of the Department of Human Services to evaluate the living skills of persons with deaf-blindness in Minnesota. The purpose of the evaluation is to provide necessary baseline data from which the individual and others can plan their futures and make informed decisions about service options. With effective skills in communication, self-evaluation, and the ability to identify, locate, and access resources, a person with deaf-blindness can become an independent and productive member of the community. For more information, or to make a referral, contact: FIND, Inc., 119 North 4th Street, Minneapolis, MN 55401. Tel. (612) 333-9102.

HELP PREVENT CHILD ABUSE

One way to help to make Minnesota a safer place for children and families to grow is to join with the many concerned citizens who are members of the

Minnesota Committee for Prevention of Child Abuse. Along with membership, receive the *Prevention News*. Find out about the numerous opportunities for volunteer involvement. Contact: MCPCA, 1934 University Avenue West, St. Paul, MN 55104. Tel. (612) 641-1568.

PUBLICATIONS/RESOURCES

Parent Guides, The National Information Center for Children and Youth with Handicaps (NICHCY), 1990. Two free guides (in a series) are available: (1) *A Parent's Guide to Doctors, Disabilities, and the Family*--how to select a primary health care provider, how to foster parent-doctor relationships, and suggests how doctors can work with families and schools; and (2) *A Parent's Guide to Accessing the ERIC Resource Collection*--how to find and use the resources of the Educational Resources Information Center (ERIC) and the many clearinghouses within ERIC. Available from: NICHCY, P.O. Box 1492, Washington, D.C. Tel. (703) 893-6061.

Inclusion News, Centre for Integrated Education and Community, is a periodical about information and events relating to the inclusion of students with disabilities in the classroom and communities. Contact: Marsha Forest, Centre for Integrated Education and Community, 24 Thome Crescent, Toronto, Ontario, M6H 2S5.

Becoming Informed Consumers: A National Survey of Parents' Experience with Respite Services, J. A. Knoll, Human Services Research Institute, 1989. This survey of families who subscribe to the *Exceptional Parent Magazine* clearly demonstrated that respite care is a valuable resource for families who are able to utilize it. However, families often have substantial problems working out the details of obtaining this support. The authors of the report noted that "lack of flexibility, arbitrary limits on use of the service, the inability of the 'service system' to consistently respond to crises, all point to services which have not yet taken the concept of parental empowerment to heart. This experience is mirrored in the families' evaluation of the degree to which they are active partners in the planning and implementation of the programs which affect their families." A review of the literature confirmed that there is little evidence that the majority of respite programs are consistent with the values of consumer empowerment and control, e.g., professionals assuming the role of telling the parents not only

what they need, but what they can have. "People become powerful by having experiences that affirm their abilities; people are made powerless through experiences which demean their competencies," the author stated. The report recommends respite care models that are based on establishing equal partnerships between parents and professionals which assume two basic premises: 1) all families and persons with disabilities are potentially willing and capable to make responsible decisions; and 2) families know best what will make their life easier, more productive, and secure for their child. Copies of the report are available from: Human Services Research Institute, 2336 Massachusetts Avenue, Cambridge, MA 02140. Tel. (617) 876-0426.

PUBLIC HEARINGS ON HEALTH CARE ACCESS SCHEDULED

The Minnesota Health Care Access Commission has scheduled Public Hearings across Minnesota. All interested individuals or groups are invited to testify before the Commission. The Commission was created by the 1989 Minnesota State Legislature to develop and recommend a plan to provide access to health care for all state residents. The remaining hearings are scheduled in the following areas:

Minneapolis: September 13, 1990 (6:00 to 9:00 p.m.) Sabathani Community Center, 310 East 38th Street, Minneapolis. Contact: Barb Mathison (612) 297-5980.

Brainerd: September 27, 1990 (3:00 to 7:00 p.m.) Crow Wing County Social Service Center. Contact: Gayle Anderson (218) 828-3987.

Blue Earth: October 16, 1990 (3:00 to 7:00 p.m.) Blue Earth Community Library, Community Room. Contact: Frank Lawatsch (507) 526-3273.

Rochester: October 17, 1990 (3:00 to 7:00 p.m.) Kaufman Center for Continuing Education. Contact: not available.

EVENTS

September 11, 1990

A workshop on "Personal Futures Planning," for case managers, service providers, family members,

advocates, and friends, will be held at the Radisson South, Bloomington. Personal Futures Planning is a process used to create a vision of a more desirable future for individuals dependent on human services. The intent of the workshop is to provide an overview of the process. Fee: \$60.00. Contact: OPAL Corporation, 706 S. Robert Street, St. Paul, MN 55107

September 21-23, 1990

The ARC Minnesota State Conference, "Coping Today--Creating Tomorrow: Practical Skills and Future Planning for Families," will be held at Cragun's near Brainerd. For more information, contact: ARC Minnesota, 3225 Lyndale Avenue South, Minneapolis, MN 55408. Topics include: working with parents with a developmental disability, positive parenting, estate planning, adult sibling advocacy, personal futures planning, sexuality, win-win negotiating, and chemical dependency. Tel. (612) 827-5641, or (800) 582-5256, toll-free.

September 21-22, 1990

A retreat/workshop for parents who have a child with special needs ages birth through six years. The retreat is being sponsored by the Family Facilitator Project. The purpose of the retreat is to provide parents access to information and resources which will be helpful to them in raising a child with special needs. It will be held at the Fair Hills Resort near Detroit Lakes, MN. There is a \$5 registration fee which includes all materials, food and lodging. For further information, contact Jacki Karch, West Central ECSU, 1001 E. Mount Faith, Fergus Falls, MN 56537. (218) 739-3273 or (701) 234-5975.

October 25, 1990--St. Cloud Civic Center, St. Cloud
November 1, 1990--Earle Brown Center, St. Paul

A workshop "Individual Assessment and Career Planning for Supported Employment" will be held in the two locations listed above. This event is sponsored by the Minnesota Alliance for Training and Technical Assistance, the Department of Education, and the Department of Human Services. Fee: \$50.00, which includes materials and lunch. Contact: Minnesota Technical Assistance Resource Network on Supported Employment at (612) 626-7220.

The State Developmental Disabilities (DD) Program Office has acquired several education, training and resource materials. The following materials may be borrowed from the State Office only, located at the address on the front sheet of the State Supplement section of this newsletter. Tel. (612)296-4618.

LENDING LIBRARY SELECTIONS

Living Well with Epilepsy, Robert J. Gummit, Demos Publications, 1990. This book is designed to give people with seizures, and others who share life with them, the information and the outlook necessary to live successfully with epilepsy. As stated by the author, "To live successfully with a chronic medical problem requires extra thought, good planning, and realistic self-assessment. . . . If you present yourself as competent and responsible, you will be treated that way. . . . Our patients have taught us how epilepsy can be made a part of a very fulfilling life." This compact volume represents 30 years of experience largely through Minnesota's Comprehensive Epilepsy Program, University of Minnesota Hospitals, Gillette Children's Hospital, and Abbott-Northwestern Hospital.

Topics covered include: living successfully; understanding epilepsy; causes and treatment; finding high quality care; being an effective member of a health care team; importance of complete and accurate diagnosis; medication; the first choice; surgical options; being prepared; first aid; seizures in infants, coping with epilepsy in childhood, teens, and adulthood; sexuality; pregnancy; the workplace; insurance and benefits;

legal rights; resources; research; and hope for today and the future. Available on a three-week loan basis, or may be purchased for \$11.95 (plus \$0.62 postage and handling; and Minnesota residents add \$0.72 sales tax) payable to: Epilepsy Education, 5775 Wayzata Boulevard, Suite 255, Minneapolis, MN 55416.

Teaching People with Developmental Disabilities, Oregon Research Institute, Research Press, 1988. This is a video training series designed to help teachers, staff, volunteers, or family members learn four behavioral techniques while teaching functional living skills. The series features four videotapes and four workbooks. Each video includes numerous scenes of actual training sessions in which teachers are shown working with students. A helpful narration offers valuable guidelines and points out the correct and incorrect use of techniques presented in the program. As an integral part of the program, the workbooks provide helpful readings, discussion material, and content review questions. The four-part series consists of: Tape 1, Task Analysis; Tape 2, Prompting; Tape 3, Reinforcement; and Tape 4, Error Correction.

Metropolitan Council DD Program
Mears Park Centre
230 East Fifth Street
St. Paul, MN 55101

If you no longer wish to receive this newsletter, please call (612) 291-6364, or write to the DD Program, Metropolitan Council Mears Park Centre, 230 East Fifth Street, St. Paul, MN 55101

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