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WorkLife

A Publication on Employment and People with Disabilities

Commemorative Edition



ADA

A Special Issue



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Ramey, Ph.D.	Sharon L.	Director & Professor	Civitan International Research Center	University of Alabama at Birmingham	1719 Sixth Avenue South	Birmingham, AL 35294	(205) 934-8900
Regan	John B.	Assemblyman, Nevada State			3200 East Cheyenne Avenue	North Las Vegas, NV 89115	(702) 643-6060
Riggins	Wesley	Sr. Mult Family Housing Analyst			3900 Wisconsin Avenue, N.W.	Washington, D.C. 20016	(202) 752-7436
Righter	Aase J.	Assistant Executive Director	American Network of Community Options and Research		4200 Evergreen Lane - Suite 315	Annandale, VA 22803	(703) 642-6614
Roach, Ed.D.	Virginia	Deputy Executive Director	National Association State Boards of Education		1012 Cameron Street	Alexandria, VA 22314	(703) 684-4000
Roberts	Beverly	Project Director	Mainstreaming Medical Care	The Arc of New Jersey	985 Livingstone Avenue	North Brunswick, NJ 08002	(908) 246-2525
Robinson	Debbie		Speaking for Ourselves		One Plymouth Meeting - Suite 430	Plymouth, PA 19462	(610) 825-4592
Robinson, R.N.,Ph.D.	Cordelia	Director	JFK Center for Developmental Disabilities	Univ. of Colorado Health Science Ctr.	4200 East Ninth Avenue, Box C234	Denver, CO 80262	(303) 270-7224
Rogan	Pat	Professor	Indiana University	School of Education	902 W. New York Street	Indianapolis, IN 46202-5155	(317) 274-6806
Rosen, Ph.D.	Daniel B.	President and Chief Executive Officer	ARI, Inc.		174 Richmond Hill Avenue	Stanford, CT 06902-5696	(203) 324-9258
Rosenthal	Donna M.	Executive Director	National Down Syndrome Society		666 Broadway - Suite 810	New York, NY 10012	(212) 460-9330
Rubenstein, Esq.	Leonard S.	Director	The Judge David L. Bazelon Center for Mental Health Law		1101 15th St., N.W. - Suite 1212	Washington, D.C. 20005	(202) 467-5730
Rusch, Ph.D.	Frank	Director	Transition Institute at Illinois	College of Education	University of Illinois 110 Education Bldg. - 1310 S. 6th St.	Champaign, IL 61820	(217) 333-2325
Sandford	E. Halsey	Executive Vice President	Res-Care, Incorporated		1300 Embassy Square	Louisville, KY 40299	(502) 491-3464
Scarlett	Joseph K.	Rehabilitation Counselor	Olathe District Schools		12612 West 104 Terrace	Overland Park, KS 66215	(913) 492-7973
Seelman, Ph.D.	Katherine	Director	N'tnl Institute on Dis. & Rehab. Research	Dept. of Education Rm. 3060 - Mary E. Switzer Bldg.	330 C Street, S.W.	Washington, D.C. 20201	(202) 205-8134
Seagle	Lynne	Executive Director	Hope House Foundation		100 W. Plume St. - Suite 244	Norfolk, VA 23510	(804) 625-6161
Seltzer	Bud	Chair		Minnesota Arc Housing Committee	1285 S. Cleveland Avenue	St. Paul, MN 55116	(612) 698-8321

Shoultz	Bonnie	Asso. Director for Training & Info.	Center for Human Policy	Syracuse University	200 Huntington Hall - Suite 200	Syracuse, NY 13244-2340	(315) 443-4323
Shulz	Otto	Sr. Information Analyst			3900 Wisconsin Avenue, N.W.	Washington, D.C. 20016	(202) 752-7436
Siantz, Ph.D.	Mary Lou	Associate Professor	School of Nursing	Indiana University	1111 Middle Drive #403	Indianapolis, IN 46202	(317) 274-7557
Siegenthaler	Linda A.	Senior Economist	U.S. Public Health Service Agency for Health Care Policy Research	Executive Office Center	2101 E. Jefferson Street, Suite 502	Rockville, MD 20852	(301) 594-1357
Simon, Ph.D.	Rosalyn	Director Project Action		National Easter Seal Society	1350 NY Ave., N.W. - Suite 613	Washington, D.C. 20005	(202) 347-3066
Simonds	Loren				567 Hawthorne N.E.	Salem, OR 97310	(503) 945-5837
Skirtic, Ph.D.	Thomas	Professor of Special Education		University of Kansas	Dole 3001 Building	Lawrence, KS 66045	(913) 864-4954
Smith	Gary A.	Director of Special Projects	N'tnl Association of State Directors of	Developmental Disabilities Services	6893 S. Miller Street	Littleton, CO 80127	(303) 973-6210
Smith	Patricia	Executive Director	N'tnl Parent Network of Disability		1600 Prince St., - Suite 115	Alexandria, VA 22314	(703) 684-6763
Smith	Vicki	Deputy Director	NAPAS		900 2nd Street, N.E. - Suite 211	Washington, D.C. 20002	(202) 408-9514
✓ Smull, Ph.D.	Michael	Director	DDSU - Univ. of Md. School of Medicine		630 W. Fayette Street	Baltimore, MD 21201	(410) 328-2140
Snell	Mary Jo	Director	AVATRAC		11111 East Mississippi Avenue	Aurora, CO 80012-3136	(303) 360-0025
Sparling	William J.	Sr. Evaluator	Housing and Community Issues - RCED	General Accounting Office	820 First Street, N.E. - Suite 150	Washington, D.C. 20002	(202) 512-6796
Spicer	John				151 Martin St., 2nd Floor	Syracuse, NY 13208	
Spitalnik, Ph.D.	Deborah	Executive Director	University Affiliated Prog. of New Jersey	Robert Wood Johnson Medical School Brookwood II - 45 Knightbridge Road	P.O. Box 6810	Piscataway, NJ 08855-6810	(908) 235-4447
Stewart	Louis, J.D.	Attorney	Coordination and Review Section	Civil Rights Division	U.S. Department of Justice	P.O. Box 66118 Washington, D.C. 20035	(202) 616-7779
✓ Stone	Robyn	Deputy Assistant Secretary	Office of the Assistant Secretary for Planning and Evaluation (ASPE/HHS)	Room 424-E - HHH Building	Dept. of Health and Human Services	200 Independence Avenue, S.W. Washington, D.C. 20201	(202) 690-6443
Stoneman, Ph.D.	Zolinda	Director	University of Georgia		Dawson Hall	Athens, GA 30602	(706) 542-4827
Strouse, M.A.	Michael A.	Executive Director	Community Living Opportunities		6900 W. 80th Street	Overland Park, KS 66204	(913) 341-9316
Swanson, M.D.	Mark	Director	University of Arkansas	University Affiliated Program	1120 Marshall, Suite 306	Little Rock, AR 72202	(501) 320-3760
Terrill	Cathy Ficker	Executive	Ray Graham Association		1015 Saylor Avenue	Elmhurst, IL 60126	(708) 530-4554
Thaler	Nancy	Deputy Secretary for MR	PA Department of Public Welfare		Health and Welfare Bldg. - Rm. 333	Harrisburg, PA 17150	(717) 787-3700
Thompson	E. Duane	Executive Director	Association for Individual Development		309 W. New Indian Trail Court	Aurora, IL 60506	(708) 844-5040

Torner	Ronald	Coordinator of Employment Services	Institute for Human Development		2220 Holmes Street	Kansas City, MO 64108	(913) 642-8149
Turnbull, Ed.D.	Ann P.	Co-Director	Beach Center		3111 Haworth Hall	Lawrence, KS 66045	(913) 864-7600
Turnbull	Rud	Co-Director	Beach Center		3111 Haworth Hall	Lawrence, KS 66045	(913) 864-7600
Turner	Brenda K.				20 Legislative Plaza	Nashville, TN 37243	(615) 698-0908
Tymchuk, Ph.D.	Alexander J.	Associate Professor and Director	SHARE/UCLA Project Neuropsychiatric Institute & Hospital	Center for the Health Sciences	University of California, Los Angeles	760 Westwood Plaza Los Angeles, CA 90024	(310) 825-0026
Villa, Ed.D.	Richard	President	Bayridge Education Consortium		6 Bayridge Estates	Colchester, VT 05446	(802) 878-8957
Volpe	L. Carl	Deputy Director of Human Resources for Health Policy and Legislation		National Governor's Association	444 North Capitol St., N.W.-Suite 267	Washington, D.C. 20001	(202) 624-5300
Walsh, Ph.D.	Kevin	Director of Research - CHD	Developmental Disabilities Center	Morristown Memorial Hospital	100 Madison Avenue - Box 60	Morristown, NJ 07960	(201) 971-4095
Ward	Nancy	Chairperson	Self-Advocates Becoming Empowered		2501 N Street #411	Lincoln, NE 68510	(402) 476-0002
Wardwell	Robert C.	Director Division of Coverage Policy	HCFA/HHS		6325 Security Boulevard - Rm. 400	Baltimore, MD 21207	(410) 966-5659
Wehman, Ph.D.	Paul	Director	Virginia Commonwealth University	Rehabilitation Research and Training Ctr.	P.O. Box 2011	Richmond, VA 23284-0000	(804) 367-1851
Wessels	Marilyn	President	Schools Are For Everyone, Inc.		P.O. Box 9503	Schnectady, NY 12309	(518) 377-8074
Wetherow	David	Executive Director	Association for Community Living-Winnipeg		1706-90 Garry Street	Winnipeg, Manitoba R3C 4J4 CANADA	(204) 947-1249
Whiteman	Marci				2813 Lee Oaks Court, Unit 301	Falls Church, VA 22046	(703) 573-6052
Wieck, Ph.D.	Colleen	Executive Director	Minnesota Developmental Disabilities Council	Centennial Office Bldg.- Room 300	658 Cedar Street	St. Paul, MN 55155	(612) 296-9964
Williams, M.P.A.	Valerie N.	Associate Director	Univ. Affiliated Program of Oklahoma	Univ. of Oklahoma-College of Medicine	P.O. Box 26901	Oklahoma City, OK 73190-3042	(405) 271-2688
Williams	Robert	Commissioner	Admin. on Developmental Disabilities Admin. for Children & Families	Rm. 329-D - HHH Building	200 Independence Ave., S.W.	Washington, D.C. 20201	(202) 690-6590
Williams	Virginia	Senior Advisor	Community Planning	Georgetown University UAP	2233 Wisconsin Ave., N.W. - Suite 215	Washington, D.C. 20007	(202) 338-1698
Williamson	Gail G.	Disability Advisor, Section 811	Supported Housing for Persons with Disabilities	U.S. Dept. of Housing and Urban Dev.	451 7th Street, S.W. - Room 6116	Washington, D.C. 20410-0001	(202) 708-2866
Yaffee	Harriet	Executive Director	ICON Employment Services		110 N. Royal Street, #508	Alexandria, VA 22314	(703) 548-4048
Young	Tony	Director	Residential Serv. & Comm. Supports	Government Relations Division Amer. Rehabilitation Association	1350 I St., N.W. - Suite 670	Washington, D.C. 20005	(202) 789-5700
Ziring, M.D.	Philip R.	Chairman	Department of Pediatrics	Pacific Presbyterian Medical Center	2351 Clay Street - Suite 501	San Francisco, CA 94115	(312) 633-6530

STAFF

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Green	Angie D.	Clerk-Typist	Room 5325 - Wilbur J. Cohen Bldg.	330 Independence Avenue, S.W.	Washington, D.C. 20201	(202) 619-3636
Lion	Terry	Clerk-Typist	Room 5325 - Wilbur J. Cohen Bldg.	330 Independence Avenue, S.W.	Washington, D.C. 20201	(202) 619-3636
Krause	Fred J.	Special Assistant to the Executive Director	Room 5325 - Wilbur J. Cohen Bldg.	330 Independence Avenue, S.W.	Washington, D.C. 20201	(202) 619-3463
Mnatzakanian	Ashot P.	Family and Community Services Coordinator	Room 5325 - Wilbur J. Cohen Bldg.	330 Independence Avenue, S.W.	Washington, D.C. 20201	(202) 619-3636
Pride	John L.	Acting Deputy Executive Director	Room 5325 - Wilbur J. Cohen Bldg.	330 Independence Avenue, S.W.	Washington, D.C. 20201	(202) 619-0634
Roach	Laverdia T.	Prevention Coordinator	Room 5325 - Wilbur J. Cohen Bldg.	330 Independence Avenue, S.W.	Washington, D.C. 20201	(202) 619-3636
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PARTICIPANTS LIST

PARTICIPANTS
THE PRESIDENT'S REFORM AGENDA
AND
PEOPLE WITH MENTAL RETARDATION
21st CENTURY REALITIES

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Patricia Allison, D.O.
Kathy Beyer
Arnold Birenbaum, Ph.D.
Peter Blanck, J.D.
David Braddock, Ph.D.
Dennis Braden
Edward Brann, M.D.
Herbert J. Cohen, M.D.
Allen Crocker, M.D.
Jeannie Cummins
Elaine M. Eklund
Ethan Ellis
Neal Glaser
Robert Gris
Lucy Hackney
Stanley Handmaker, M.D., Ph.D.
Alfred Healy, M.D.
Joseph Hollowell, Jr., M.D.
Ted Kastner, M.D.
Greg Kattouf
Samuel Kessel, M.D., M.P.H.
Thomas Lottman
Kathleen McGinley, Ph.D.
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Magarita Miranda, Ph.D., MPHE
Peter P. Polloni
Raymond M. Peterson, M.D.
Laverdia T. Roach
Beverly Roberts
Cordelia Robinson, R.N., Ph.D.
E. Halsey Sandford
Linda A. Siegenthaler
Deborah Spitalnik, Ph.D.
Mark Swanson, M.D.
Alexander J. Tymchuk, Ph.D.
Kevin Walsh, Ph.D.
Valerie N. Williams, M.P.A.
Philip R. Ziring, M.D.

WELFARE REFORM

Michelle Adler
Steve Bartholomei-Hill
Laurel Beedon, Ph.D.
Elizabeth M. Boggs, Ph.D.
Edward P. Burke
Tamar Heller, Ph.D.
James W. Hubbard
Matthew P. Janicki, Ph.D.
Bette Keltner, R.N., Ph.D.
Irving Martin
J. Kenneth McGill
Charlotte B. Parkinson, D.S.W.
Cliff Poetz
John L. Pride
Craig T. Ramey, Ph.D.
Sharon Landesman Ramey, Ph.D.
John B. Regan
Aase J. Righter
Leonard S. Rubenstein, Esq.
Mary Lou de Leon Siantz, Ph.D.
Loren Simonds
Rosalyn Simon, Ph.D.
Robyn Stone
Zolinda Stoneman, Ph.D.
Virginia Williams

LONG TERM CARE REFORM

Carol Beaty
Alan Bergman
Valerie J. Bradley
Robert Brown
Dennis M. Byars
Robin Cooper
M. Doreen Croser
Steve Eidelman
Martha Ford, Esq.
Joni Fritz
Glenn Fujiura, Ph.D.
James F. Gardner, Ph.D.
Robert M. Gettings
Gail Jacobs
Tecla M. Jaskulski
Ruth Katz
Cindy Kauffman
Fred Krause

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Michael Kennedy
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Paul Marchand
Isabel T. Mills
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Michael Smull, Ph.D.
Michael A. Strouse, M.A.
Nancy Thaler
E. Duane Thompson
Brenda Kaye Turner
L. Carl Volpe
Nancy Ward
Robert C. Wardwell
Marci Whiteman
Colleen Wieck, Ph.D.

HOUSING REFORM

Susan Babin
Marian J. Barber
M. Alton (Al) Barnes
Elizabeth W. Bauer
Robert E. Brown
Ken Campbell
Russell Daniels
Susan Daniels, Ph.D.
Robert G. Davies
Gunnar Dybwad, Ph.D.
Becky Donofrio
Joe Donofrio
Judy England-Joseph
Andrew F. Eustin, FAIA
Suellen R. Galbraith
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K. Charlie Lakin, Ph.D.
Margaret Milner
Ashot P. Mnatzakanian
T.J. Monroe

John O'Brien
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Bud Seltzer
Bonnie Shoultz
Otto Shulz
Gary A. Smith
William J. Sparling
Cathy Ficker Terrill
David Wetherow
Gail G. Williamson

EDUCATION REFORM

Alan Abeson, Ed.D.
Maureen E. Babula
Donald B. Bailey, Jr., Ph.D.
Louise Bauer
Amy Bennett
Gwen Benson, Ph.D.
Jane Browning
Nitina Chavan
Diane Ferguson
Marvin G. Fifield, Ed.D.
Alison Ford
Ann Forts
Hiawatha Fountain, Ed.D.
William Halloran, Ph.D.
Mike Hardman, Ph.D.
Dawn Hunter
Terry Ingram
David R. Johnson, Ph.D.
William E. Jones, Ph.D.
Cheryl Jorgensen
Naomi Karp
William R. Langner
Mark Malawer
John McClain, Ph.D.
Patricia McGill-Smith
Celane McWhorter
James Meadours
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Tom Nurney, Ph.D.
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Dolores Norley, Esq.
Liz Obermayer
Jim Piet
Virginia Roach
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Orv C. Karan, Ph.D.
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Tia Nelis
John Nietupski
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Daniel B. Rosen, Ph.D.
Frank Rusch, Ph.D.
Joseph K. Scarlett
Mary Jo Snell
Louis Stewart, J.D.
Ronald Torner
Paul Wehman, Ph.D.
Harriet Yaffee



APP 1 1994

PRESIDENT'S COMMITTEE ON MENTAL RETARDATION
U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES
Administration for Children and Families
Washington, D.C. 20201-0000

Mrs. Carol H. Rasco
Assistant to the President
for Domestic Policy
The White House
Washington, D.C. 20500

Dear Mrs. Rasco:

Thank you for agreeing to participate in the April 24-26, 1994, Presidential Forum: "The President's Reform Agenda and People with Mental Retardation -- 21st Century Reality." The Forum will be convened at the Radisson Plaza Hotel at Mark Center, 5000 Seminary Road, Arlington, Virginia. A tentative agenda accompanies this letter.

Please note that the Forum is scheduled to begin at 12:30 p.m., Sunday, April 24, 1994, and you are scheduled to speak at 11:00 a.m., Tuesday, April 26. Your expertise will be of great benefit to the participants in developing quality recommendations to the President.

I look forward to seeing you at the Forum.

Sincerely,

Gary H. Blumenthal
Executive Director

Enclosure

MEMORANDUM

To: All Participants

From: Julie Furman
Conference Planner

Subject: President's Committee on Mental Retardation Conference (PCMR)
April 24-26, 1994

Date: March 11, 1994

We are delighted that you have agreed to attend the President's Committee on Mental Retardation Conference. KRA Corporation (KRA) has been selected as the logistics contractor for this conference. The following information includes details relevant to your participation in the conference.

CONFERENCE SCHEDULE INFORMATION

Preregistration will begin Sunday morning, April 24, 1994 at 10:00 a.m. A tentative agenda is enclosed for your information and review. The conference will begin Sunday, April 24, 1994, promptly at 12:30 p.m.

CONFERENCE REGISTRATION FEE

A registration fee of \$75.00 is being collected from all the attendees of the PCMR Conference. This fee must be collected prior to the conference registration cut-off date of April 11, 1994.

HOTEL AND LODGING INFORMATION

A single sleeping room has been reserved in your name at The Radisson Plaza Hotel at Mark Center for arrival on Saturday, April 23, if you are from out of town. The special single sleeping room rate is \$113.00, inclusive of all tax. **You will be responsible for all charges (e.g., room and tax, valet, movies, mini-bar, room service, laundry, and all phone calls) upon checkout.** Self-parking is available at the hotel at a rate of \$3.50 per day; valet parking is \$10.00 per day; local guest parking is \$1.50 per hour - \$6.00 maximum.

KRA is not authorized to guarantee your hotel room for late arrival. It is imperative that you call the hotel directly at (703) 845-1010 to guarantee your room with your personal credit card information if you will be arriving after 6:00 p.m. Please refer to the group name "**President's Committee on Mental Retardation.**" Check-in time is 3:00 p.m. and check-out time is 12:00 noon. If you do not need sleeping room accommodations, please call the hotel to cancel the reservation.

TRAVEL ARRANGEMENTS

If you are travelling from out of town, and need assistance with your travel arrangements, KRA's corporate travel agency, Montgomery Travel Center, is available to assist you. Their phone numbers are: (301) 587-2121 or (800) 862-3322. **You are responsible for all travel costs.**

GROUND TRANSPORTATION

A Radisson Plaza Hotel brochure and a Metrorail Pocket Guide are enclosed for your information. The hotel offers complimentary van shuttle service from National Airport every 30 minutes from 10 after and 40 after every hour. The cost of a taxi from National Airport is approximately \$13.00 and the cost of a taxi from Dulles International Airport is approximately \$60.00. The Washington Flyer offers transportation from both National and Dulles airports. Please refer to the attached schedule for information.

SPECIAL NEEDS

Please advise KRA if you require any special accommodations or assistance for this meeting (ADA accessible sleeping room, large-type meeting materials, sign language interpretation or readers.)

It is our pleasure to be of assistance to you. If you have any questions regarding the logistics of this meeting, please contact me at (301) 495-1591.

REGISTRATION FORM

1. Participant registration fees include admission to all sessions and conference sponsored meal functions.
2. Guest registration fee includes Sunday's Networking Social and Monday's Forum Luncheon.
3. Only one (1) person may register per form.
4. All fees are per person.
5. This form must be accompanied by payment (check, money order, or government purchase order.)

[illegible]

MI

Title/Position

Company/Affiliation

Mailing Address

City

State

Zip Code

Telephone

Fax



Please indicate any special needs (including dietary)

Please register me for the President's Committee on Mental Retardation Conference.

- April 24-26, 1994
Alexandria, Virginia
Radisson Plaza Hotel at Mark Center
Ph: (703) 845-1010
(April 11, 1994)*

***Registration Cut-Off Date**

- Registration fee: \$75.00**

Total Amount Due \$ _____

Please Check One:

- ☐ Enclosed is Check # _____ payable to KRA Corporation.
Please write registrant(s) name on check.
- ☐ Enclosed is a Government Purchase Order # _____

Please complete one registration form per person on purchase order.

Payment is due with registration form.

KRA Corporation
Attn: Conference Services Department
1010 Wayne Avenue, Suite 850
Silver Spring, Maryland 20910
Ph: (301) 495-1591

*** Registrations received after 5 p.m. (EST) of the cut-off dates will be processed on-site. Please bring your payment with you to the conference registration desk.**

**Fax registrations will not be accepted.
No exceptions.**

Received Date _____ Entered _____ Check # _____
Reg ID # _____ Amt Rec'd _____

***PRESIDENT'S COMMITTEE ON MENTAL RETARDATION
U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES
Administration for Children and Families
Washington, D.C. 20201-0001***

***A PRESIDENTIAL FORUM:
THE PRESIDENT'S REFORM AGENDA
AND
PEOPLE WITH MENTAL RETARDATION --
21st CENTURY REALITIES***

***TENTATIVE AGENDA
April 24-26, 1994***

***RADISSON PLAZA HOTEL
AT MARK CENTER
5000 SEMINARY ROAD
ALEXANDRIA, VIRGINIA, 22311
(703) 845-1010***

copy-- 10-15 drive
escalator
1 floor cover bench →
15 (pickup)

**PRESIDENTIAL FORUM:
THE PRESIDENT'S REFORM AGENDA AND PEOPLE WITH
MENTAL RETARDATION - 21st CENTURY REALITIES**

PURPOSE

The twofold purpose of this conference is to provide a forum for selected national leaders in the field of mental retardation and related developmental disabilities to:

- a) discuss the impact of six of the President's major reform areas on citizens with mental retardation and related developmental disabilities; and*
- b) chart the direction for future activities, policies, and implementation strategies.*

The issues identified and recommendations developed will form the basis for the next President's Committee on Mental Retardation Annual Report to the President.

The six selected reform area topics are:

Health Care Reform and People with Mental Retardation and Related Disabilities;

Welfare Reform and People with Mental Retardation and Related Disabilities;

Long-Term Care Reform and People with Mental Retardation and Related Disabilities;

Housing Policy Reform and People with Mental Retardation and Related Disabilities;

Education Reform and People with Mental Retardation and Related Disabilities; and

Employment/Financing and People with Mental Retardation and Related Disabilities.

The President's Committee on Mental Retardation (PCMR) acknowledges and extends appreciation to the following organizations and agencies for their co-sponsorship of the Presidential Forum: "The President's Reform Agenda and People with Mental Retardation -- 21st Century Realities."

*The Administration on Aging (AoA)
U.S. Department of Health and Human Services*

*The National Institute on Disability
and Rehabilitation Research (NIDRR)
Office of Special Education and Rehabilitative Services
U.S. Department of Education*

*The Social Security Administration (SSA)
U.S. Department of Health and Human Services*

*The Administration on Developmental Disabilities (ADD)
Administration for Children and Families
U.S. Department of Health and Human Services*

*The National Institute of Child Health
and Human Development (NICHD)
National Institutes of Health
U.S. Department of Health and Human Services*

President's Committee on Mental Retardation (PCMR)

***A Presidential Forum:
The President's Reform Agenda
and
People with Mental Retardation --
21st Century Realities***

***Radisson Plaza Hotel
April 24-26, 1994***

Tentative Agenda

Sunday, April 24, 1994

10:00 a.m.

Registration

PLENARY SESSION

12:00 Noon

Greetings and Purpose

Gary H. Blumenthal
Executive Director

President's Committee on Mental Retardation
Vice Chair

President's Committee on Mental Retardation

Valerie Bradley

President

Human Services Research Institute, Cambridge, Massachusetts

Welcome

Vincent C. Gray

Director

Department of Human Services, District of Columbia

12:15 p.m.

Administration for Children and Families: Vision and Goals

Mary Jo Bane, Ph.D

Assistant Secretary for Children and Families

U.S. Department of Health and Human Services

12:30 p.m.

Panel I: Setting Visions and Goals

Moderator: David J. Dunn

President

The Arc, Rochester, Minnesota

Self-Advocates' Perspective

T.J. Monroe

Knoxville, Tennessee

Tia Nelis

Wayne, Illinois

Parents' Perspective

Koquese Collins

Detroit, Michigan

Don and Dawn Merriman

Salina, Kansas

Linda Charlton

Bel Air, Maryland

1:30 p.m.

**PANEL II: Implications of the President's Reform Agenda on
Citizens with Mental Retardation and Related Disabilities**

Moderator: Valerie Bradley

President

Human Services Research Institute, Cambridge, Massachusetts

Susan Daniels, Ph.D.

Associate Commissioner

Administration on Developmental Disabilities

Katherine Seelman, Ph.D.

Director

National Institute on Disability and Rehabilitation Research

Paul Miller

Deputy Director

White House Office of Consumer Affairs

The White House

2:30 p.m. -

2:45 p.m.

BREAK

2:45 p.m.

Legislative Concerns of Consortium for Citizens with Disabilities (CCD)

Paul Marchand

Chairperson

Consortium for Citizens with Disabilities (CCD)

Tony Young

Co-Chairman

CCD Long Term Services and Support Task Force

3:15 p.m.

**Panel III: Congressional Perspectives: The Impact of Reform
Initiatives on Policies Affecting Citizens with Mental
Retardation and Related Disabilities**

Moderator: Ann Rosewater

Deputy Assistant Secretary for Policy and External Affairs

Administration for Children and Families

Impact of Reform Initiatives on Policies Affecting Citizens with
Mental Retardation and Related Disabilities

Andy Imparato

Counsel

Senate Subcommittee on Disability Policy

Christine Ferguson

Legislative Director

Office of Senator John Chafee

3:50 p.m.

Questions and Answers

4:05 p.m.

Work Group Session Assignments

William E. Jones, Ph.D.

Executive Director

American Association of University Affiliated Programs

4:15 p.m. -

4:30 p.m.

BREAK

4:30 p.m. -

6:00 p.m.

WORK GROUP SESSIONS (convening concurrent)

I. Health Care Reform and People with Mental Retardation

Leaders: David Braddock, Ph.D.

Theodore Kastner, M.D.

II. Welfare Reform and People with Mental Retardation

Leaders: Marsha M. Seltzer, Ph.D.

Sharon L. Ramey, Ph.D.

III. Long-Term Care Reform and People with Mental Retardation

Leaders: Steve Eidelman

Robert Gettings

IV. Housing Reform and People with Mental Retardation

Leaders: K. Charlie Lakin, Ph.D.

Jay Klein

V. Education Reform and People with Mental Retardation

Leaders: Jan Nisbet, Ph.D.

Diane Ferguson, Ph.D.

VI. Employment/~~Financing~~ and People with Mental Retardation

Leaders: David M. Mank, Ph.D.

William Kiernan, Ph.D.

6:00 p.m.

RECESS

6:30 p.m. -

NETWORKING SOCIAL

7:30 p.m.

Monday, April 25, 1994

7:30 a.m.

Registration/Continental Breakfast

8:30 a.m.

PLENARY SESSION

Moderator: John Pride

Acting Deputy Executive Director

President's Committee on Mental Retardation

Goals 2000... School to Work

Judith E. Heumann

Assistant Secretary

Office of Special Education and Rehabilitative Services

U.S. Department of Education

Community Inclusion and Older Americans with Mental Retardation and
Related Developmental Disabilities

Fernando M. Torres-Gil

Assistant Secretary for Aging

U.S. Department of Health and Human Services

Cultural Diversity and Citizens with Mental Retardation and
Related Disabilities

Robert Williams

Commissioner

Administration on Developmental Disabilities

Administration for Children and Families

9:05 a.m. -

Questions and Answers

9:15 a.m.

9:15 a.m.

WORK GROUPS SESSIONS, continued

10:45 a.m.

Health Care Reform

Welfare Reform

Long-Term Care Reform

Housing Reform

Education Reform

Employment/Financing Reform

10:45 a.m. -

BREAK

11:00 a.m.

(At the discretion of the Group Leader)

11:00 a.m. -

WORK GROUPS

12:15 p.m.

Health Reform and Welfare Reform, (*convening jointly*)

Long-Term Care Reform

Housing Reform

Education Reform

Employment/Financing Reform

12:30 p.m. -

FORUM LUNCHEON

2:00 p.m.

Introduction of Keynote Speaker

Mary Jo Bane, Ph.D.

Assistant Secretary for Children and Families

U.S. Department of Health and Human Services

15-20

KEYNOTE: "A Time for National Reform: Preparation for the
21st Century"

The Honorable Donna E. Shalala

Secretary

U.S. Department of Health and Human Services

Chair

President's Committee on Mental Retardation

2:15 p.m. -
3:45 p.m.

WORK GROUPS

Education Reform and Employment/Financing Reform, (*convening jointly*)
Health Care Reform
Welfare Reform
Long-Term Care Reform
Housing

BREAK

(At the discretion of the Group Leader)

4:00 p.m. -
5:30 p.m.

WORK GROUPS

Long-Term Care Reform and Housing Reform, (*convening jointly*)
Health Care Reform
Welfare Reform
Education Reform
Employment/Financing Reform

5:30 p.m.

RECESS

Tuesday, April 26, 1994

8:00 a.m. -
8:30 a.m.

Registration/Continental Breakfast

8:30 a.m. -
10:00 a.m.

WORK GROUP - Concluding Session

Health Care Reform
Welfare Reform
Long-Term Care Reform
Housing Reform
Education Reform
Employment/Financing Reform

10:00 a.m. -
11:00 a.m.

BREAK

10:15

12:00

70

11:00 a.m. -
12:30 p.m.

FORUM SUMMATION

Moderator: Gary Blumenthal
Executive Director
President's Committee on Mental Retardation

Work Group Reports and Recommendations
(Chairperson for each work group)

Summary and Acknowledgement of Recommendations
Glen Fujiira, Ph.D.

Introduction of Closing Speaker
Stanley Herr, Esq.
Kennedy Public Policy Fellow
Office of Domestic Policy
The White House

Speaker: Carol Rasco
Assistant to the President for Domestic Policy
The White House

Summary and Closing Remarks
Valerie Bradley
Human Services Research Institute

11:15
Seating
Personal Story
Relate
Impediments
Discussion/NA
etc.

12:30 p.m.

ADJOURNMENT

Thank you for your participation!

PARTICIPANTS
THE PRESIDENT'S REFORM AGENDA
AND
PEOPLE WITH MENTAL RETARDATION
21st CENTURY REALITIES

HEALTH CARE REFORM

Kathy Beyer
Arnold Birenbaum, Ph.D.
Peter Blanck, J.D.
David Braddock, Ph.D.
Dennis Braeden
Edward Brann, M.D.
Herbert J. Cohen, M.D.
Allen Crocker, M.D.
Jeannie Commins
Elaine M. Eklund
Ethan Ellis
Harriet Fox
Neal Glaser
Robert Gris
Lucy Hackney
Stanley Handmaker, M.D., Ph.D.
Alfred Healy, M.D.
Joseph Hollowell, Jr., M.D.
Ted Kastner, M.D.
Greg Kattouf
Samuel Kessel, M.D., M.P.H.
Thomas Lottman
Kathleen McGinley, Ph.D.
Merle McPherson, M.D.
Magarita Miranda, Ph.D., MPHE
Peter P. Polloni
Raymond M. Peterson, M.D.
Laverdia T. Roach
Beverly Roberts
Cordelia Robinson, R.N., Ph.D.
E. Halsey Sandford
Linda A. Siegenthaler
Deborah Spitalnik, Ph.D.
Mark Swanson, M.D.
Alexander J. Tymchuk, Ph.D.
Kevin Walsh, Ph.D.
Valerie N. William, M.P.A.
Philip R. Ziring, M.D.

WELFARE REFORM

Michelle Adler
MaryLee Allen
Patricia Allison, M.D.
Steve Bartholomei-Hill
Laurel Beedon, Ph.D.
Phyllis Berman, Ph.D.
Elizabeth M. Boggs, Ph.D.
Curtis J. Decker, J.D.
Tamar Heller, Ph.D.
James W. Hubbard
Matthew P. Janicki, Ph.D.
David Kass
Bette Keltner, R.N., Ph.D.
Irving Martin
J. Kenneth McGill
Charlotte B. Parkinson, D.S.W.
Cliff Poetz
John M. Pride
Craig T. Ramey, Ph.D.
Sharon Landesman Ramey, Ph.D.
John B. Regan
Aase J. Righter
Leonard S. Rubenstein, Esq.
Marsha Mailick Seltzer, Ph.D.
Mary Lou de Leon Siantz, Ph.D.
Loren Simonds
Rosalyn Simon, Ph.D.
Robin Stone
Zolinda Stoneman, Ph.D.
Travis Thompson, Ph.D.
Virginia Williams

LONG TERM CARE REFORM

Carol Beaty
Alan Bergman
Valerie J. Bradley
Robert Brown
Dennis M. Byars
Mike Chapman
Robin Cooper
M. Doreen Croser
Derrick Dufresne
Steve Eidelman
Celia Feinstein
Martha Ford, Esq.
Joni Fritz
Glen Fujirua, Ph.D.

James F. Gardner, Ph.D.
Robert M. Gettings
Gail Jacobs
Tecla M. Jaskulski
Ruth Katz
Fred Krause
Frank Laski
Dick LePore
Michael Kennedy
Joel M. Levy
Paul Marchand
Isabel T. Mills
Debbie Robinson
Lynn Seigel
Michael Smull, Ph.D.
Michael A. Strouse, M.A.
Nancy Thaler
E. Duane Thompson
Brenda Kaye Turner
L. Carl Volpe
Nancy Ward
Robert C. Wardwell
Marci Whiteman
Colleen Wieck, Ph.D.

HOUSING REFORM

Susan Babin
M. Alton (Al) Barnes
Elizabeth W. Bauer
Robert E. Brown
Ken Campbell
Russell Daniels
Susan Daniels, Ph.D.
Robert G. Davies
Gunnar Dybwad, Ph.D.
Becky Donofrio
Joe Donofrio
Judy England-Joseph
Andrew F. Eustin, FAIA
Suellen R. Galbraith
Charlie Galloway
Vicki Grosch
Dennis E. Haggerty, Esq.
David S. Harre
Reggie Jaramillo
Lawrence A. Kane, Jr., Esq.
Jay Klein
K. Charlie Lakin, Ph.D.
Margaret Milner

William Mitchell
Ashot P. Mnatzakanian
T.J. Monroe
John O'Brien
Patrick Rafter
Bud Seltzer
Bonnie Shultz
Gary A. Smith
William J. Sparling
Cathy Ficker Terrill
David Wetherow
Gail G. Williamson

EDUCATION REFORM

Alan Abeson, Ed.D.
Maureen E. Babula
Donald B. Bailey, Jr., Ph.D.
Louise Bauer
Amy Bennett
Gwen Benson, Ph.D.
Jane Browning
Nitina Chavan
Diane Ferguson
Alison Ford
Hiawatha Fountain, Ed.D.
William Halloran, Ph.D.
Mike Hardman, Ph.D.
Dawn Hunter
Terry Ingram
David R. Johnson, Ph.D.
William E. Jones, Ph.D.
Cheryl Jorgensen
Naomi Karp
William R. Langner
Ruth Luckasson, J.D.
Mark Malawer
John McClain, Ph.D.
Patricia McGill-Smith
Celane McWhorter
James Meadours
Christina Metzler
Jan Nisbet, Ph.D.
Dolores Norley, Esq.
Liz Obermayer
Virginia Roach
Donna M. Rosenthal
Tom Skirtic
Bena L. Smith
Vicki Smith

Page 5

Ann P. Turnbull, Ed.D.
Rich Villa, Ed.D.
Marilyn Wessels

EMPLOYMENT

Robert Anderson, Ph.D.
Tom Baffuto
Dr. Richard Balser
Kammie Barfield
Yolande Bestgen
George N. Bouthilet, Ph.D.
Michael Collins
Barbara Coppens
Sharon Davis, Ph.D.
Gordon Dawson
Rick Douglas
David Dunn
Terry Edelstein
Larry Goldberg, Esq.
Judith Gran, Esq.
Chris Grandy
Jim Harper
Paul Hippolitus
Ron Inlow
Fred Isbister
Sharman Davis Jamison
Pat Juhrs
Orv C. Karan, Ph.D.
William E. Kiernan, Ph.D.
David M. Mank, Ph.D.
John McDonnell, Ph.D.
William McLaughlin
Tia Nelis
John Nietupski
Stephanie J. Powers
Ian Pumpian, Ph.D.
Pat Rogan
Daniel B. Rosen, Ph.D.
Frank Rusch, Ph.D.
Mary Jo Snell
Louis Stewart, J.D.
Ronald Torner
Paul Wehman, Ph.D.
Harriet Yaffee
Steve Zivolich

*President's Committee on Mental Retardation
and the
United States International Council on Mental Retardation
and Related Developmental Disabilities*

Invite you to Attend a Special Dinner to Honor

*Mrs. Marianna Beach
and
Dr. Gunnar Dybwad*

*on
Monday, April 25, 1994*

*at the
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Yes, _____ will attend the special Monday, April 25th dinner.

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*For more information, please contact:
Fred J. Krause
President's Committee on Mental Retardation
(202) 619-3463*





**A special meeting will be held on the future of the
United States International Council on
Mental Retardation and
Related Developmental Disabilities
on Tuesday, April 26, 1994
from 1:30 - 3:30 p.m.
following the closing of the
PCMR Presidential Forum.**

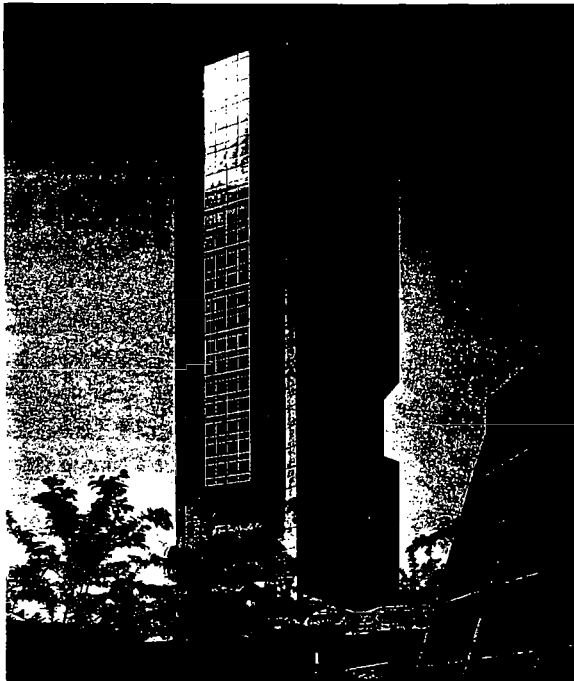
I will attend the special meeting on USICMR.

Plaza Bolivar

I cannot attend but would like more information.

**For more information, please contact:
Fred J. Krause
U.S. Department of Health and Human Services
Administration for Children and Families
President's Committee on Mental Retardation
Room 5325, Cohen Building
Washington, D.C. 20201-0001
Phone: (202) 619-3463
Fax: (202) 205-9519**



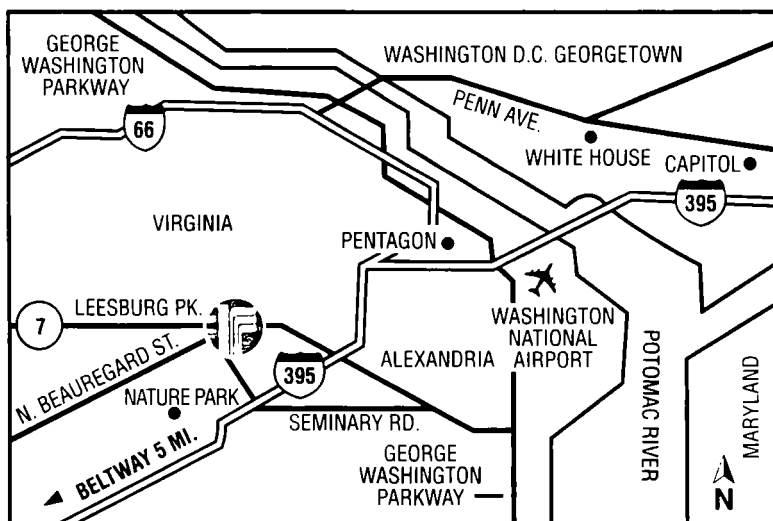


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**Employment/Financing Reform
Presidents Committee on Mental Retardation**

**The President's Reform Agenda and People with Mental Retardation:
The 21st Century Realities**

Introduction

For the past 15 years there has been a growing emphasis on integrated employment (competitive and supported) opportunities for persons with mental retardation and developmental disabilities. The accomplishments of the supported employment effort are considerable in that thousands of persons, who in the past would have been considered as being unemployable, have become employed in community job settings where the predominance of their co-workers are persons without disabilities. Recent studies and reports have raised the question as to whether there has been a slowing of the movement from segregated to integrated employment settings (Mank, in press; McGaughey, Kiernan, McNally, Gilmore & Keith, 1994; Wehman & Kregel, 1993; West, Revell, & Wehman, 1992).

A recently published national study reports that in 1991 seven out of ten persons served in day and employment programs are served in segregated settings. Of the projected 1.02 million persons served nationally, approximately 700,000 are served in segregated or non-work settings (McGaughey et al., 1994). In addition, during the 1991 survey period, more persons entered segregated settings than integrated employment settings. The challenge for expanding integrated employment includes both creative redirection of existing resources as well as an expanding commitment on the part of all of the key stakeholders (parents, people with disabilities, employers, service providers, and the general public) to the movement toward integrated employment opportunities for all persons with disabilities.

The following report offers recommendations for people with disabilities, advocates, family members, employers, and the President's Committee on Mental Retardation (PCMR) as we address the issues related to expansion of integrated employment for persons with mental retardation and developmental disabilities. It should be noted that employment cannot be dealt in isolation. It must be coordinated with other major life activities such as

community living, integrated leisure recreation, and other support services. The following report, while recognizing the interrelationship between major life areas, focuses recommendations predominantly on issues of employment and the need to assure that all persons with mental retardation and developmental disabilities realize greater economic independence through real work. The emphasis of the report is upon serving those individuals who have the highest support needs with a strong emphasis upon the provision of supports in work settings where persons without disabilities are employed.

Presidential Forum Procedures

The Presidential Forum, sponsored by the President's Committee on Mental Retardation, met April 24 through 26, 1994 in a series of six groups of people with disabilities, family members, advocates, employers, professionals, and other interested parties to discuss the impact of six of the President's major reform areas on citizens with mental retardation and related developmental disabilities and to chart the direction for future activities, policies and implementation strategies. The six selected areas were health care reform, welfare reform, long term care reform, housing policy reform, education reform, and employment/ financing.

A panel of 34 persons participated in the employment/financing reform working group. The meetings used an open discussion format with the emphasis on identifying the purpose, goals and objectives for employment/financing for persons with mental retardation and related developmental disabilities. The group considered issues related to education reform jointly with members of that panel to discuss issues related to school to work and recognizes the relationship of the objectives identified here to each of the other five selected reform areas.

Findings in Employment/Financing Reform

The following presents the purpose, general goals, individual objectives and recommendations to PCMR regarding the employment of persons with mental retardation in the United States.

Purpose of Employment /Financing Reform:

Increase the number of persons with mental retardation and developmental disabilities who enter work in business/industry

settings (target in 5 years an additional 400,000 persons entering integrated employment)

Goals:

1. Assure individual involvement, choice and control of supports for all persons with mental retardation and related developmental disabilities
2. Invest in community capacity building to realize integrated employment for all persons with mental retardation and related developmental disabilities
3. Assure funding sources which promote integrated employment
4. Require integrated employment goals in all transition plans
5. Assure that all federal policies and practices promote integrated employment

Goal 1 Assure individual involvement, choice and control of supports for all persons with mental retardation and related developmental disabilities

Rationale

The passage of the Americans with Disabilities Act [P.L. 101-336] reinforces the need to assure access by persons with disabilities to all of the services, resources, and employment available to persons without disabilities. It also reinforces the concept that persons with disabilities must play an active role in developing and implementing their supports and services. There is reaffirmation of the concepts of consumer empowerment and inclusion of persons with disabilities in all life activities through the legislative language included in the Rehabilitation Act Amendments of 1992 [P.L. 102-569], the Individual with Disabilities Education Act [IDEA; P.L. 101-476], and the Administration on Developmental Disabilities authorizing legislation.

The active involvement of persons with disabilities, their family members, and their significant others has been shown to be an effective means of developing a coordinated and comprehensive response to issues such as school inclusion, integrated employment, community membership and assurance that persons with disabilities have equal opportunities in all community experiences. The growing emphasis on the development of personal futures planning, whole life planning, or person centered planning supports the belief that the central person in the planning process must be the individual with a disability, not just in the

acceptance of the plan, but in the initiation, identification of objectives, and agreement on outcomes related to a service and support plan (Butterworth, Hagner, Heikkinen, Faris, DeMello, & McDonough, 1993; O'Brien, 1987).

The legislative intent over the last five years clearly creates a stronger role for people with disabilities and families at all levels. The implementation of this effort has been somewhat varied in that much of the financial support for programs continues to go directly to providers rather than consumers and family members. The selection of the supports and services are more often than not in the control of persons other than the consumer and family members. Some attempts at creating personalized family supports, use of monies to support individual choice and selection, and direct payment to individuals with disabilities are beginning to reinforce the practice of direct support to individuals so that they may implement their own services or purchase their own supports (Bradley & Knoll, 1990). In some cases, consumers may choose not to receive direct fiscal supports but rather be able to select within a service system the actual supports that they feel they need. In this latter situation the consumer may be provided a range of services from which to select while in the earlier scenario the consumer may seek out supports from any source and pay for them directly. In either case, the control and choice belongs to the individual not to the service provider or an external group of individuals.

The movement away from professionally driven services to a individually designed support systems is clearly articulated in national policy. The implementation of these services at the individual service provider level and the abilities to get states to provide resources that are individually focused is evolving. The following recommendations for the President's Committee on Mental Retardation would strongly encourage that there be a greater amount of effort exerted in moving from a service system designed to provide slots or fixed structures to one which looks at customization and the provision of supports for all persons with mental retardation and related developmental disabilities. To this end the following objectives are offered:

Objectives

Objective 1.1. Provide support and training for people with disabilities in all planning processes (IEP, ITP, IWRP) relating to school transition and rehabilitation

Objective 1.2. Change financial controls so that people with disabilities control expenditures of monetary and personnel resources (e.g. vouchers, choice of services provided etc.)

Objective 1.3. Develop service and support standards which reflect individual choice and control rather than compliance to staffing patterns, physical facilities and structured training schedules exclusively.

Objective 1.4. Monitor the implementation of the Rehabilitation Act Amendments to assure that any person seeking employment supports and services is offered those services in an integrated setting and that the individual rehabilitation plan includes the consumer in all stages of development of the plan.

Objective 1.5. Assure that transition planning includes full involvement of people with disabilities and other interested persons as well as educators, adult service providers (public and not for profit when appropriate and consistent with the wishes of the consumer) and that the outcomes reflect the interests and wishes of the consumer.

Objective 1.6. Develop research which identifies best practices in assuring informed and participatory decision making for persons with disabilities, developing effective methods of identifying interests and preferences and establishing ways of documenting levels of satisfaction and quality of life for persons with disabilities

Goal 2. Invest in community capacity building to realize integrated employment for all persons with mental retardation and related developmental disabilities

Rationale

As in the first goal, developing integrated employment opportunities for persons with mental retardation and developmental disabilities is the responsibility of not just the individual service provider but the individual, family members, employers, and the community at large. The emphasis upon expansion of integrated employment opportunities (that is competitive and supportive employment where the predominance of the co-workers are persons without disabilities) has been present for the past decade and a half. Historically, the responsibility for the development of employment opportunities was perceived to be that of the public rehabilitation agency or the non-profit community rehabilitation provider. Research now has documented new employer leadership and 'family friend' networks as well as the existing general employment services network are effective tools in expanding employment opportunities for persons with disabilities.

With the broadening of the involvement of others in the employment process, it is essential that there be an active way for employers and other interested parties in becoming involved in the creation of jobs for persons with disabilities. In some instances, employers are willing and interested in becoming involved through a recognition of the capabilities and skills that persons with disabilities bring to an employment setting. While in other instances, the emphasis of the Americans with Disabilities Act may serve as the incentive for employers to reach out to persons with disabilities. In either case, there needs to be a flexible strategy for assuring that employers can play a role in creating job opportunities and assisting persons with disabilities in not only entering employment but also advancing in the work setting.

The accomplishments of the system change efforts through the Rehabilitation Services Administration had been documented through several studies (McGaughey et al., 1994; Schalock, McGaughey & Kiernan, 1993; West, Revell & Wehman, 1992). Unfortunately, the expectation that systems change would occur in a five year cycle does not appear to have been justified (Mank, in press). More recently, data are showing the continuation of a dual system of employment (Mank, in press; McGaughey et al., 1994). It is critical that the emphasis of all employment services be consistent with the intent of the Rehabilitation Act Amendments, the Americans with Disabilities Act, IDEA, and other similar federal legislation which calls for the development of opportunities for persons with disabilities to be employed in real work settings. The creation of such settings will require innovative and unique partnerships between employers, community rehabilitation programs, and persons with disabilities.

Though historically there have been partnerships among employers and community rehabilitation provider groups, the growing recognition that all persons with disabilities can be served in integrated settings will require a broadening of the view of these relationships. Creative options for support directly to employers may serve to stimulate the growth of integrated employment for persons with disabilities. Other flexible alternatives need to be stimulated and developed. The role of the federal government as well as state initiatives can serve to enhance the creativity of the general public and the community employer by providing seed money and supports to employers, community, rehabilitation providers, consumers, and other interested parties in expanding integrated employment.

The following objectives offer some strategies for the creation of a more flexible approach to the design, development and expansion integrated employment for all persons with mental retardation and related developmental disabilities.

Objectives

Objective 2.1. Develop demonstration programs which stimulate alternative ways of supporting persons with disabilities in obtaining integrated employment (employer sponsored programs, personal placement supports, head hunter designs, employment collaboratives etc.)

Objective 2.2. Require new priorities and project monies to be available at federal and state levels to support replication of best practices in integrated employment.

Objective 2.3. Provide integrated employment option grants and incentives to community entities which expand integrated employment options for persons with disabilities

Objective 2.4. Assist community rehabilitation programs in closing their segregated settings

Objective 2.5. Develop support options for persons transitioning from one job to another and in career advancement

Objective 2.6. Assure that there are sufficient training monies at the federal and state levels such that key stakeholders develop the skills and competencies related to the development of integrated employment for persons with mental retardation and related developmental disabilities.

Goal 3. Assure funding sources promote integrated employment

Rationale

Some of the concern raised about establishing integrated employment by community rehabilitation providers centers around limited monies available to develop integrated employment opportunities and inadequate funding streams to assure ongoing supports.

Recent data have shown that at the state level, 80 cents in every dollar are used to reimburse segregated employment settings while at the federal level 90 cents in every dollar spent in day and employment services go toward supporting segregated employment outcomes (McGaughey, Kiernan, McNally, & Gilmore, 1993). Through initiatives such as the Rehabilitation Services Administration supported employment systems change grants there

have been increases in the number of persons entering supported employment. However, the short duration of those projects, that is, a five year systems change effort, may be inadequate to assure that there is a permanent shift in emphasis from segregated to integrated settings (Mank, in press; McGaughey et al., 1994; Wehman & Kregel, 1993).

Furthermore, a study recently completed by the Institute for Community Inclusion (1994) while showing a greater percentage of persons entering integrated employment than those entering segregated employment, in absolute numbers more persons entered segregated settings than integrated employment in 1991. These data reflect the efforts of community rehabilitation providers in 1991 some 8-10 years after the initiative on supported employment was begun.

One of the concerns raised by parents and persons with disabilities is the apprehension relating to entering integrated employment and experiencing job failure or a need to leave a position and having no alternatives. Often this is referred to as concerns relating to the absence of a 'safety net' or some capacity to provide assurances that individuals, if they are in an integrated setting and need to change a job, will receive supports and services in order to make that change. Initial data have shown that of those leaving integrated employment, approximately one-third return to segregated outcomes while one-third go into other integrated settings (generally with less supports provided) and one-third remain at home or enter a waiting list (McGaughey et al., 1994). Much of the support provided by community rehabilitation providers for individuals who have left integrated employment is done through the providers own resources rather than through public monies (Mental Retardation/ Developmental Disabilities agency or the Rehabilitation Services Administration state vocational rehabilitation agency), another issue of inadequate funding.

The predominance of the fiscal support for day and employment services at a state level comes from state Mental Retardation and Developmental Disabilities agencies. It is estimated that approximately 5,800 community based rehabilitation providers are located throughout the United States serving about 1.02 million persons (McGaughey et al., 1994). Of this number, more than eight out of ten persons are reported to have a diagnosis of mental retardation or developmental disabilities. The most frequent source of support for integrated settings in these community based rehabilitation programs are the state Vocational

Rehabilitation agencies while the state Mental Retardation and Developmental Disabilities agencies are the most frequent supporters of segregated settings in the community based rehabilitation provider systems (McGaughey et al., 1994). Part of the support for segregated settings may come through Medicaid. The restriction on the use of Medicaid money to support only those individuals who have been or are at risk of institutionalization limits the number of persons who can be supported through this system. Though many states have supported employment as an approved service under their Medicaid waiver, it is seldom utilized as an employment outcome at the state level (Smith & Gettings, 1993).

A frequent concern raised by families, consumers, and providers is the apprehension associated with the loss of benefit, particularly medical benefits but also cash benefits. The current work incentives of the Social Security Administration are not fully understood and are inadequately utilized by those receiving Supplemental Security Income (SSI) benefits. Of those receiving Disability Insurance benefits (SSDI), similar work incentives do not exist. Often persons receiving SSDI benefits places themselves at risk of loosing all of their DI benefits and then having to petition to receive SSI benefits if they are what is referred to as a 'dual' beneficiary. The structure of the Work Incentives of the Social Security Administration must be reviewed and revised such that they are consistent for SSI and SSDI beneficiaries and that these incentives mirror those received by persons who are blind.

If the emphasis on integrated employment is to continue it is critical that the money provided at the federal, state and local levels be focused on supporting integrated employment outcomes for persons with mental retardation and developmental disabilities. Additionally, all federal initiatives, particularly those associated with employment as in the case of the National Service Corp. and the School to Work efforts through the US Department of Labor should include a role for persons with mental retardation and related developmental disabilities.

Finally, as noted in the following objectives, careful consideration must be given to the capacity of states to run a dual system, that is, supporting both segregated and integrated employment outcomes. A much more aggressive approach towards expanding integrated employment will require a thoughtful allocation of resources supporting segregated programs. State funding practices must reflect the values of the federal legislation and thus move to

supporting integrated employment as the desired outcome for all persons with mental retardation and developmental disabilities.

The following lists the objectives associated with the creation of funding sources to promote integrated employment.

Objectives

Objective 3.1. Require that RSA monies (including Section 110 monies and those monies received from state allocations as part of the required match for participation) support integrated employment and consumer choice

Objective 3.2 Remove all limitations to use of Medicaid monies for integrated employment

Objective 3.3. Eradicate individual work disincentives in federal programs (as in the case of Social Security SSI and DI; assets levels must be raised, incentives expanded and opportunities for consumer control of monies expanded as in the case of capacities to purchase supports and services by the individual which reflect preference and interests and which will directly or indirectly lead to securing and/or maintaining a job in business/industry)

Objective 3.4. Coordinate all employment efforts at the federal level such that persons with mental retardation and related developmental disabilities are included in any employment or economic development initiative (i.e., School to Work programs, National Service Corp, etc.)

Objective 3.5. Require that state and local governments develop a comprehensive integrated employment support system for all persons with mental retardation and related developmental disabilities to be realized in ten years

Objective 3.6. Require utilization of all state funding for employment supports and services to focus on the outcome of integrated (and not segregated) employment

Goal 4. Require integrated employment goals in the transition plans for all students for whom employment is the goal after high school

Rationale

With the increase emphasis upon inclusion in community schools, many students with mental retardation and related developmental disabilities are having greater opportunities to relate to students without disabilities in both academic and non-academic classroom settings. The emphasis through IDEA on the transition planning process beginning at age 16 and preferably at age 14, has resulted in planning for the movement from school into adult life to

begin at an earlier age for all students with disabilities. A concern that has been raised about the transition implementation is the limitations of the employment opportunities for persons who are moving from school into adult life. For some students who have participated in an integrated or inclusive school experience, the only outcome recommended at the time of exit from school is participation in a segregated day or employment setting.

It is critical that transition outcomes reflect both the needs and interest of the students as well as the opportunities to continue the experiences of the student in an integrated settings. Recent data have shown that approximately 3% of the new entries into mental retardation and developmental disabilities day and employment programs annually are students who have moved from school into adult life (McGaughey et al., 1993). Some are scheduled to enter segregated settings. In order to address this issue it is important to advocate for the establishment of integrated employment objectives for students who are not seeking post secondary outcomes as part of their transition plan. These objectives will be consistent with the educational experiences of the student and are reflective of what students and parents have expected in their school curriculum, that is, an opportunity to relate to others and to have a job.

In order to accomplish this goal, there would need to be a closer working relationship between schools and community rehabilitation providers as well as an increased knowledge among key stakeholders (educators, adult service providers, consumers, family members, and employers) as to effective strategies for collaborative transition planning for students with disabilities. Emphasis upon knowledge among these key stakeholders of methods of developing integrated employment opportunities, approaches to job accommodation, strategies for job creation, and designs for provision of ongoing job supports as part of the transition process will be essential.

Establishing integrated employment as an outcome in the transition process will require that schools, the business community, and adult service agencies work more collaboratively together in planning for the continuation of the supports for an individual in a work setting as they move from school into adult life. In order to accomplish this, the following objectives have been identified.

Objectives

Objective 4.1. Require that training (preservice and inservice) in integrated employment be provided to all educators

Objective 4.2. Provide technical assistance to consumers, family members, employers and school systems in development of integrated employment options for all students

Objective 4.3. Have integrated employment (and not placement into segregated settings) as an outcome of all transition plans

Objective 4.5. Insure participation of students with disabilities in the implementation of the School to Work Act

Goal 5. Assure that all federal policies and practices promote integrated employment

Rationale

Over the past five years, significant legislation at the federal level has been passed reflecting the issues of independence, inclusion, consumer control, and whole life planning among other items. With the passage of the Americans with Disabilities Act, IDEA, the Rehabilitation Act Amendments, and the existence of the Developmental Disabilities legislation, the intent of the federal legislation is clearly toward recognizing skills and abilities of individuals with disabilities, the incorporation of persons with disabilities at all levels in the planning and implementation of services and supports, and the full inclusion of persons with disabilities within community settings.

As was noted previously, though these legislative mandates exist, funding and reimbursement practices appear to reinforce the idea of segregation or specialized services for persons with disabilities. It is important that all monies including those administered by the Rehabilitation Services Administration, the Social Security Administration, Medicaid, and special education programs reflect the principles and values as stated in the above noted legislation. Additionally, legislative and administrative initiatives reflecting issues of creation of employment opportunities and economic development for all persons must include a role for persons with disabilities as an equal partner.

In order to assure that all federal policies and practices promote integrated employment, there needs to be an increased effort on building the skills and competencies of professionals

and paraprofessionals who offer supports and services to persons with disabilities. Thus, federal funding priorities in the areas of training (both preservice and inservice) must reflect an increased emphasis on interdisciplinary training focusing upon the inclusion of persons with disabilities in community settings. Additionally, research needs to be funded which assist in the identification of best practices and the documentation of current practices in the areas of integrated employment. It is critical that knowledge about current employment activities as well as identification of innovative and promising factors is vigorously pursued through national and state research activities. Documentation of the current 'state of the practice' for persons with disabilities should be part of national surveys including those relating to the census, health, secondary education, unemployment, and other national survey activities.

In order to assure that the state and federal practices promote integrated employment, there is a need for skills and competencies associated with the expanding integrated employment by the key stakeholders. In addition, there must be clear documentation of outcomes relating to choice, preference and changes in quality of life as result of federally funded system change initiatives, demonstration programs, and training projects as well as state offered employment service programs. The following objective reflect those issues.

Objectives

Objective 5.1. Require that all federal programs comply with the values expressed in IDEA, ADA, and the Rehabilitation Act Amendments of 1992

Objective 5.2. Require that all RSA monies be utilized to support integrated employment (including extended evaluation and work adjustment monies)

Objective 5.3. Assure that persons with disabilities are included in all employment program initiatives sponsored by the federal level (School to Work, National Service Corp., etc.)

Objective 5.4. Conduct studies at the national, state and local levels documenting integrated employment outcomes for person with disabilities

Objective 5.5. Assure that adequate research addressing innovations in integrated employment approaches, practices and designs are conducted at the national, state and local levels

Objective 5.6. Provide adequate training monies to support interdisciplinary preservice and inservice training activities directed at the development of the skills and competencies in integrated employment among a wide range of professionals and direct service staff.

Summary and Recommendations

In summary, the above goals and objectives state clearly the emphasis upon the expanding the role of persons with disabilities in community settings with a specific emphasis upon integrated employment opportunities for persons with mental retardation and related developmental disabilities. Further, the President's Committee on Mental Retardation is in a unique position to influence federal policy and to advocate for state adopt of policies and practices which will provide greater opportunities for persons with mental retardation and developmental disabilities to become more economically independent and included in integrated work settings in the future. Following is a summary of specific objectives which the President's Committee should address during the coming years.

Recommendations for PCMR:

1. Advocate that all programs be consistent and coordinated with a focus on inclusion, consumer choice, and personal control of both resources and services.
2. PCMR should expand its membership to include representatives from the business community.
3. PCMR should develop an action plan reflecting the goals and objectives in these and the other reports and that this action plan will be disseminated widely
4. PCMR should also expand its membership to include other essential federal agencies including Commerce and Transportation
5. PCMR should convene a working group with a specific and continuing emphasis upon developing an employment focus within PCMR
6. PCMR should address the issues of Medicaid reform and the disincentives which this system places upon the development of integrated employment for all persons with mental retardation and related developmental disabilities
7. PCMR should work with the Department of Education in the areas of teacher preparation and the expansion of training grants to include issues related to transition and employment.

8. PCMR should advocate for research which will document current practice, identify state of the art approaches, report innovative approaches and disseminate such approaches, and support investigation which identifies effective strategies which support the values and principles expressed in federal legislation.
9. PCMR should continue to place the emphasis upon the development of employment options for persons with the highest support needs.

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