

DRI *News*

Special Edition
2005 Symposium

A Newsletter from the Disability Research Institute

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5 Return to Work

6 Disability Determination Process

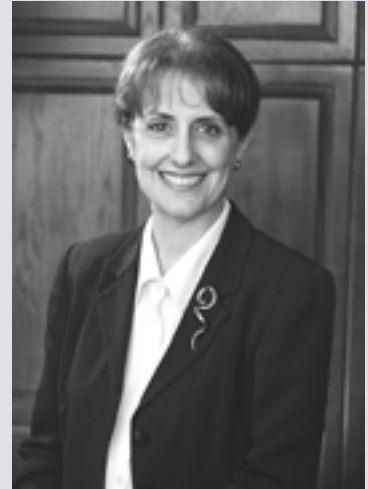
8 Youth and Transition to Work

10 Critical Research Agenda

UNIVERSITY OF ILLINOIS AT URBANA-CHAMPAIGN

From the Director...

This special edition of *DRI News* presents an overview of our very successful annual symposium, which was held this past April in Washington, D.C. The focus of this year's symposium was the Comprehensive Work Opportunity Initiative: An Interactive Symposium on Overcoming Multiple Barriers to Employment. We were honored to once again have Martin Gerry of the Social Security Administration deliver the keynote presentation, which set the tone for the stimulating discussions and the four panel presentations that followed, each addressing an overarching policy question relating to return to work, the disability determination process, youth and transition to work, or the critical research agenda.



Tanya M. Gallagher

The feedback we received from the Symposium evaluations was highly positive. I would like to extend my sincere thanks to the panelists and moderators who participated in the Symposium and whose expertise contributed so importantly to meaningful and informative discussions related to disability and employment.

We hope you enjoy reading about the Symposium in our newsletter and that you will also visit the DRI website to view a more detailed synopsis of the Symposium, including links to slides that were included in the presentations. Again, we truly appreciate the time and effort of all those who contributed to making the Symposium a success.

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2005 Annual Symposium Highlights

The Disability Research Institute held its 2005 Symposium, *SSA Disability Programs: Comprehensive Work Opportunity Initiative, An Interactive Symposium on Overcoming Multiple Barriers to Employment*, on April 5, 2005, at the National Press Club in Washington, D.C. The Symposium brought together nationally recognized leaders from the research, federal government, and disability communities to discuss the disability determination process, return to work and transition to work for individuals with disabilities, and the Ticket to Work and Work Incentives Program as they relate to facilitating employment. The Symposium was interactive with panel discussions and audience participation addressing these important topics. Related DRI-sponsored research projects were also presented in poster sessions that maximized opportunities for interactive discussions.

The symposium opened with Martin Gerry, Deputy Commissioner, Office of Disability and Income Security Programs, who presented an overview of the Comprehensive Work Opportunity Initiative: Overcoming Multiple Barriers to Employment, which highlighted eight significant barriers that people face when trying to go back to work (see Figure 1 on page 4). Gerry said that many factors influence a person's decision to work besides the prospect of an income, such as wanting to be more actively involved in society. Gerry identified eight significant barriers to employment, including:

1. Psychological impact of the disability process
2. Physical impact of delayed access to health care
3. Lack of access to training and employment services
4. Premature loss of benefits
5. Loss of ongoing employment supports
6. DI cash cliff and SSI asset limits
7. Job loss and difficulty of reinstatement, and
8. Work-related overpayments.

According to Gerry, "This is not an exhaustive list of barriers and not all people with disabilities face all of these barriers. However, if you leave any of the barriers there, you fail. The key question is not whether you can remove some barriers, but can you remove enough barriers to ensure that an individual who is trying to decide to make a work effort has the encouragement to do it."

Trust is also an important factor in the return to work process. "The trust between the beneficiaries and the government as a whole is not high," said Gerry. "People believe if they take a risk or move away from the apparent benefit structures that are currently in place, somehow they will be trapped or tripped or taken advantage of. We have to make the case to people." The agency is using various strategies to deal with these barriers, such as regulations, the way in which current policies and procedures operate, and other initiatives that include over payment prevention efforts and expanding the effective availability of resources and information for persons with disabilities. Figure 1 on page 4 illustrates the barriers to employment along with efforts that are addressing those barriers.

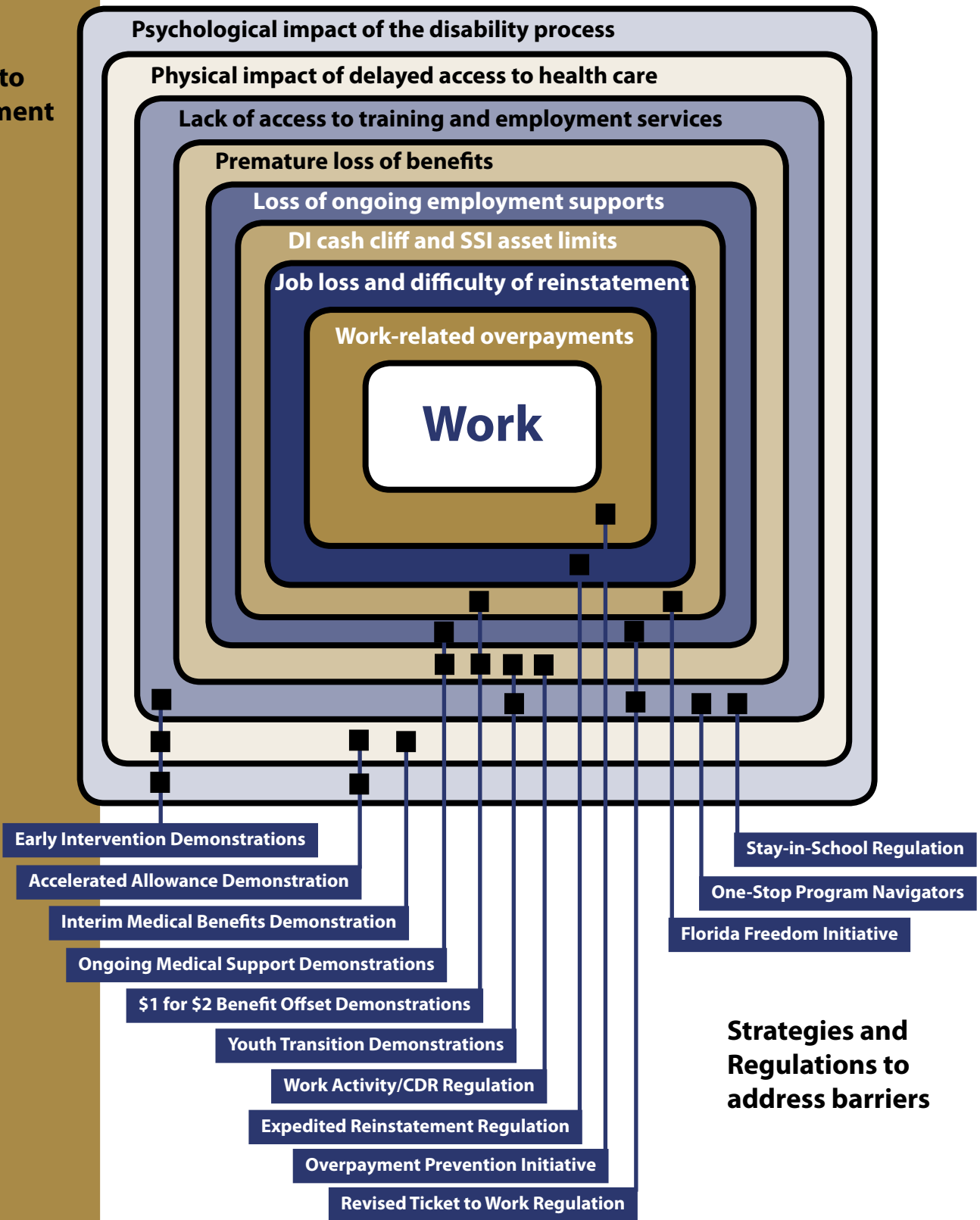


Martin Gerry

"The key question is ... can you remove enough barriers to ensure that an individual who is trying to decide to make a work effort has the encouragement to do it?"

Figure 1: Comprehensive Work Opportunity Initiative: Overcoming Multiple Barriers to Employment

Barriers to Employment



Session One: Return to Work

The first session focused on return to work issues and addressed the questions: *What are your reactions to the currently identified barriers to return to work in the Comprehensive Work Opportunity Initiative? What other barriers are there (if any) that need to be addressed and what recommendations would you make to SSA regarding strategies that should be employed to decrease or eliminate these barriers?*

Pam Mazerski, Associate Commissioner, Office of Program Development and Research, served as moderator. The panelists included Bobby Silverstein, Director, Center for the Study and Advancement of Disability Policy; Doug Kruse, Director, Program for Disability Research, Rutgers University; John Halliday, Senior Program and Policy Specialist, Institute for Community Inclusion, University of Massachusetts; and Dorothy Watson, Independent Consultant.



Bobby Silverstein began the discussion by describing the Gradual Reduction Choice Approach, an approach he has developed in partnership with Allen Jensen. This proposal suggests that individuals—rather than policy makers or bureaucrats—be allowed to determine whether they want to use the current beneficiary payment system which includes the cash cliff for earnings above SGA, or be provided with an option that will result in a gradual reduction in benefits at a level below SGA but maintain an individual's continued attachment to the program. Their proposal had five policy objectives:

1. Retain the strict eligibility criteria for disability determination;
2. Provide information so that people can choose between the current system and the gradual reduction choice option;
3. Make the SSI and SSDI work incentives more comparable;
4. Have a uniform work incentive policy; and
5. Provide a mechanism for continued attachment to SSI, SSDI, Medicare and Medicaid.

Doug Kruse presented a demand-supply analysis that identified factors that should be considered relative to the return to work of persons with disabilities. On the supply side, a review of disability programs in nine countries found that those countries with time-limited and partial disability benefits have higher employment rates for persons with disabilities and that the availability of working tax credits may also facilitate return to work. Kruse suggested that further attention should be given to Telework and contingent and part-time job opportunities



as the flexibility in these types of jobs helps individuals with disabilities cope with therapy schedules, possible transportation difficulties and other time and energy issues. "A favorable trend on the demand side is the continuing expansion of both computers and new information technologies in the workplace," shared Kruse. "A significant factor on the demand side is the corporate culture.

(continued)

John Halliday, Doug Kruse, Dorothy Watson, Bobby Silverstein, Pam Mazerski, and Martin Gerry.

Doug Kruse

People with disabilities, even with good employment skills, can encounter barriers in the workplace due to ingrained attitudes that can exist within companies.” Kruse suggested some employer policies that may be beneficial such as rejecting “one-size-fits-all” rules, emphasizing job autonomy, and reward systems that reinforce inclusion of persons with disabilities.



Pam Mazerski

Dorothy Watson highlighted some of the challenges in the implementation of the Ticket to Work program. Long standing challenges include the agency’s strict eligibility criteria, delayed access to health care, potential premature loss of benefits, and uncertainty regarding the reinstatement process. There are also periodic complaints that Social Security offices do not always understand all the opportunities available to beneficiaries that can help them to return to work. She indicated that it can be confusing that beneficiaries must prove inability to work to become beneficiaries and then are offered work incentives to help them return to work. She stressed that modifications, such as modifying the Employment Network payment system and increasing marketing efforts to beneficiaries and employers, have to be made in the Ticket to Work program in order to increase its success. For example, to date, over

50,000 potential new service providers have been contacted but only 1,200 have signed up and less than 400 out of these 1,200 have accepted tickets to provide services.

John Halliday added that many of the institutions that we look to to assist return to work may not provide real opportunities for the economic engagement of persons with disabilities.

Session Two: Disability Determination Process

The second session focused on the disability determination process, and was moderated by Kim Hildred, Staff Director, Subcommittee on Social Security House Ways and Means Committee. Panelists included Patricia Owens, Member, Board of Directors, National Academy of Social Insurance; John Halliday, Senior Program and Policy Specialist, Institute for Community Inclusion, University of Massachusetts; Tom Prudhomme, Division Director, National Center for Supercomputing Applications, University of Illinois at Urbana-Champaign; and Allen Heinemann,

Associate Director, Research, Rehabilitation Institute of Chicago. The panel addressed the question: *How can SSA modify or restructure the disability determination process to facilitate return to work simultaneously with determination of eligibility of benefits?*

Patricia Owens began the discussion by describing an ideal return to work determination process, stressing that interventions should be adapted in a way that creates a process to identify the number of people who can benefit and take the return to work track. For the program to be successful, the beneficiary must be involved in the process and there has to be a system that the person can rely on.

John Halliday observed that many individuals are deeply embedded within the system and this can lead to “engineered dependency.” Youth, irrespective of their family resources and background, may or may not be

positioned to transition into the next system when they are 18. “Often individuals are not thinking about what choices they have, but people are coming to them and telling them what their choices are,” said Halliday. He stressed the need for early intervention. By the time individuals with disabilities



Elaine Gilby with James Smith and Mark Green.

arrive at Social Security, he suggested, it may be too late. Also helpful would be the identification of work opportunities offering greater flexibility and potential for individualization.

Tom Prudhomme discussed how advanced information technology can inform and support the disability determination process and return to work initiatives. He presented as an example a National Center for Supercomputing Applications (NCSA)-DRI project that is exploring the feasibility of a new methodology for evaluating employment opportunities for SSDI claimants. Project objectives include building an updatable national database of publicly accessible job postings, and relating job functions or tasks to skills based on structured job analysis data. This type of technological innovation coupled with expert interaction underscores the promise of advanced technology to provide tools that can be used for both disability determination and for assisting individuals in finding employment.

Allen Heinemann discussed the need for fundamental change in the disability determination process. Heinemann began by referencing a January 2001 Social Security Advisory Board report in which major concerns about the disability determination process are described and still exist today. According to the report, inadequate tools exist to make disability determination decisions, and the growth in disability claims threatens to overwhelm the system. In addition, unexplained variations in disability determination decision-making leads to public perceptions of inequity and exposes the disability programs to accusations that decisions are not made uniformly and consistently. “Disability determination is a complex process that considers vocational and medical factors related to the person’s condition,” shared Heinemann. “For individuals with disabilities, the appeals process is a long and winding road to a decision, given that it can take up to three years for a total appeal to make its way through the system.” One concern is that the claimant may decide that the appeals process is too arduous resulting in the claim being dropped altogether. For those individuals with disabilities who persist with their claims, over half will receive benefits at appeal. Heinemann described a classification procedure, called the Classification and Regression Tree Analysis (CART) that he is using to analyze DRI-funded research project data. This procedure uses existing data to predict state DDS disability award decisions and ALJ decisions. It will be used to identify the factors that influence a claimant’s decision to appeal and determine if the residual functional capacity (RFC) instrument yields a reliable and valid measure, or if subsets of items form better measures. Finally, Heinemann and his team are also studying characteristics that distinguish awards at Step 3 of the disability determination process from awards at Step 4 and 5, and how well the Adult Needs and Strengths Assessment instrument predicts disability determination decisions.



Fred Menz, James Smith, and Mark Green.



Bobby Silverstein, Emer Broadbent, and Dorothy Watson.

(continued)

Session Three: Youth and Transition to Work

The third session focused on Youth and Transition to Work, and was moderated by Judee Richardson, Associate Director, Disability Research Institute, University of Illinois at Urbana-Champaign. The panel addressed the questions: *What are the most important issues for SSA to address to integrate and coordinate the long-term process of transitioning youth with disabilities to work? What are the educational, career planning, assistive technologies and other transition issues that need to be addressed in order to help youth with disabilities maximize their economic self-sufficiency?* Panelists included Merle McPherson, Director, Division of Services for Children with Special Health Needs, Health Resources and Services Administration; Curtis Richards, Senior Policy Fellow, Center for Workforce Development, Institute for Educational Leadership; Pamela Loprest, Senior Research Associate, The Urban Institute; and William Ebenstein, Executive Director, JFK, Jr. Institute for Worker Education at City University of New York.

Merle McPherson began the discussion by describing how legislation was rewritten to facilitate the development of community-based systems of services for children and youth with special health care needs and their families. She then described the Maternal and Child Health Bureau's six core outcomes, which are:

1. Families of children and youth with special health care needs will partner in decision-making and will be satisfied with the services that they receive;
2. Children and youth with special health care needs will receive coordinated ongoing comprehensive care within a medical home;
3. Families of children and youth with special health care needs will have adequate public and/or private insurance to pay for the services they need;
4. Children and youth will be screened early and continuously for special health care needs;
5. Community-based service systems will be organized so that families can use them easily; and
6. Youth with special health care needs will receive the services necessary to make transitions to adult life, including adult health care, work and independence.

McPherson concluded with a brief overview of the Health and Ready to Work Initiative, launched by the Maternal and Child Health Bureau in 2001 after a nine-site demonstration, which endeavors to help develop family-centered, culturally competent systems of care.

Curtis Richards presented guidelines for a successful transition of youth to work, including coordination of programs and systems within a cohesive framework. Richards outlined a guide for successful transition of youth with disabilities that includes five areas that all young people need. These are: 1) access to academic and vocational resources, 2) career preparatory assistance, 3) youth development and leadership including positive role models, peers and mentors, 4) connecting activities such as living a healthy lifestyle, financial management and asset development, and 5) family involvement in supports, to include any strong, caring adult who stays a part of the young person's life. In addition, Richards stated that youth with disabilities should have the same opportunities that youth without disabilities enjoy, with modifications to help them perform well in these situations. According to Richards, "Youth development and leadership is very important to facilitate successful



Top: Tom Prudhomme, Tanya Gallagher, Chris Erb, and Robert Rich at the poster session. Bottom: Judee Richardson with Peter Blanck.

transitions and could include positive role models and peers. Youth with disabilities should also be prepared for the different activities and duties that they will have to take care of in society, such as living beyond school.”

Pamela Loprest reviewed some of her recent analytic findings using the SSA’s National Survey of Children and Families data. Loprest stressed that family circumstances are an important context within which to study transition-age youth. She noted that more than half of these youth are from single-parent families and about half of the parents have less than a high school education. Furthermore, English is not the primary language in about 7% of families and over one-third of the families are living in poverty. Based upon her preliminary analyses, Loprest discussed avenues to improve self-sufficiency of transitioning youth. These include completion of secondary school, targeting early efforts on youth who are having trouble in school or with the juvenile justice system. She found that youth who do not receive SSI after age 18 are, on average, healthier and work more. However, a significant subset of these youth are not working or in school. They have dropped out of school and many have an arrest record and are uninsured. Loprest suggested support programs and services would help youth with disabilities who are vulnerable during the transition period.



Martin Gerry and Tanya Gallagher

William Ebenstein shared details about a CUNY youth transition project aimed at improving educational and employment outcomes of youth with disabilities. This project targets youth between the ages of 16-18 who live in the Bronx and includes the following interventions: self-determination (promotes disability awareness, decision-making and other skills), informed parental activism (parent peer mentors, networking and culturally competent peer support), physical fitness and health education (exploring relationship between fitness/health and employment outcomes), peer mentoring (social and recreational interactions with college students with disabilities), meaningful work-study experiences, travel training (to enhance access to public transportation), and active job development and placement (develop relationships with employers and refine vocational training programs).



(continued)

Session Four: Critical Research Agenda

The fourth session addressed the question: *What are the critical research and policy questions that need to be addressed in order to maximize the impact of research outcomes and policy recommendations on fully integrating persons with disabilities in the workforce and society at large?* The session was



moderated by Tanya Gallagher, Director, Disability Research Institute, University of Illinois at Urbana-Champaign. Panelists included Peter Blanck, Professor, College of Law, University of Iowa; Craig Thornton, Managing Director, Health Research, Mathematica Policy Research, Inc.; David Stapleton, Senior Research Associate, Center for Policy Research, Cornell University; and Eli Donkar, Deputy Chief Actuary, Social Security Administration.

Peter Blanck began the discussion with an emphasis on the need for attitudinal changes and a reduction in skepticism to ensure that people with disabilities get equal and fair opportunities for employment. “There needs to be a basic attitudinal change in the way we think about disability in this

country. Without such a change, it will be very difficult to make good programs work,” stated Blanck.

Craig Thornton stressed the need to think about a broader systems change in order to improve the full integration of persons with disabilities in the work force. He believes that Employment, Experience, Education and Expectations (the 4 E’s) of SSA beneficiaries should be examined in an effort to understand why beneficiaries would change their lives by leaving the rolls for work, especially after having gone to great lengths to prove that they cannot work. Thornton noted that it is necessary to understand all the factors (emotional and financial) involved in an individual’s decision to work, the reasons behind applying for benefits and also employer expectations and demands of individuals with disabilities in the work force.

David Stapleton impressed upon the audience that a bold test of work incentives for people with disabilities is needed. Current work disincentives are very strong and efforts to break down barriers to employment, such as the Ticket to Work Program, have had limited success. According to Stapleton, the most efficient policy is likely a mix of work incentives and efforts to address other barriers and he recommended testing several versions of such a design.

The session concluded with Eli Donkar highlighting some critical research questions by providing information on variations between beneficiaries on the basis of age, diagnostic group, and reason for termination of benefits. He stated that the major unanswered question was, “How can we go about getting people back to work on an individualized basis?” Donkar concluded by suggesting researchers address questions such as: Is there an upper bound on return to work for people with disabilities on SSA disability rolls? Is early intervention the key to successful employment activity and migration off disability benefits? Can existing administrative data tell us more? Are there matches of existing data that can be leveraged into something more? Can we delay the onset of benefit receipt through effort at the front end?

Allen Heinemann, Tom Prudhomme, John Halliday, Patricia Owens, and Kim Hildred.

Monroe Berkowitz Honored

Monroe Berkowitz, the outgoing director of the Program for Disability Research at Rutgers University, was recognized for his many contributions to the DRI at a dinner following the DRI Executive Committee meeting on April 4, 2005. Pictured below are Berkowitz with (top) Tanya Gallagher and Pam Mazerki; (middle right) Tanya Gallagher; and (bottom) Virginia Reno and Elaine Gilby.



DRI photos

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