

“Emotional and Behavioral Health in Persons with Mental Retardation/Developmental Disabilities: Research Challenges and Opportunities”

November 29 – December 1, 2001
Doubletree Hotel, Plaza I and II
Rockville, MD

Sponsors:

*NINDS, NIMH, NICHD, NIH Office of Rare Diseases,
Joseph P. Kennedy Jr. Foundation*

DAY 1: Thursday, November 29th

7:15 AM	REGISTRATION/BREAKFAST outside conference room	
8:00 AM	Welcome	Audrey Penn, Acting Director, NINDS Duane Alexander, Director, NICHD Richard Nakamura, Dep. Dir., NIMH
8:20 AM	Workshop Format Workshop Goals	Giovanna Spinella James Harris
8:30 AM	Opening Remarks	Eunice Kennedy Shriver Executive Vice President Joseph P. Kennedy Jr. Foundation

OVERVIEW SESSIONS

SESSION 1: RESEARCH OPPORTUNITIES AND CHALLENGES

8:35 AM	Introduction	Travis Thompson
8:45 AM	Behavior and Genetics	Jonathan Flint
9:00 AM	Neuroimaging	Judith Rumsey
9:15 AM	Mechanisms of Brain Plasticity and Mental Retardation Syndromes	William Greenough
9:30 AM	Psychosocial Issues	Sharon Ramey
9:45 AM	Questions/Issues for Working Group Discussions	
9:55 AM	BREAK	

SESSION 2: EPIDEMIOLOGY

10:10 AM	Introduction	James Harris
10:20 AM	Concepts and Issues with Respect to Epidemiological Studies of Mental Retardation	Sir Michael Rutter
10:35 AM	Rates and Types of Psychopathology: Lessons from Mental Retardation Syndromes	Elisabeth Dykens
10:50 AM	Considerations for the Epidemiology of Emotional and Behavioral Disorders in Persons with Cognitive Disabilities	Vincent Campbell
11:05 AM	New Service Delivery Systems: Relationship to Epidemiological Studies	David Braddock
11:20 AM	Questions/Issues for Working Group Discussion	
11:30 AM	BUFFET LUNCH Sponsored by: Association of University Centers of Disabilities National Fragile X Foundation National Organization on Fetal Alcohol Syndrome National Tuberosus Sclerosis Association	

- **SESSION 3: DIAGNOSIS/ASSESSMENT**

12:30 PM	Introduction	Bryan King
12:40 PM	New Ideas, Assessment Instruments, and Dual Diagnosis	Steven Reiss
12:55 PM	Instrument Development-psychosocial aspects	Catherine Lord
1:10 PM	Functional Analysis	Brian Iwata
1:25 PM	Diagnosis in Specific Syndromes	Carl Feinstein
1:40 PM	Questions/Issues for Working Group Discussion	

- **SESSION 4: ETHICAL CONSIDERATIONS
(ASSENT/CONSENT/SOCIAL POLICY/LEGAL)**

1:50 PM	Introduction	Norm Fost
2:10 PM	Assent/Consent/Surrogate Decision Making	Robert Dinerstein
2:25 PM	Federal Response to the NBAC Report	William Raub
2:40 PM	The Minimal Risk Rule	Robert M. Nelson
2:55 PM	Questions/Issues for Working Group Discussion	
3:05 PM	BREAK	

- **SESSION 5: INTERVENTIONS RESEARCH**

3:30 PM	Introduction	Mark Lewis
3:40 PM	Psychopharmacology	Michael Aman
3:55 PM	Psychosocial Interventions	Wayne Fisher
4:10 PM	Quality of Life Outcomes	Marsha Seltzer
4:25 PM	Questions/Issues for Working Group Discussion	

- **SESSION 6: RESEARCH DESIGN**

4:35 PM	Introduction	Mark Appelbaum
4:45 PM	Psychopharmacology Research Design	C. Keith Connors
5:00 PM	Pediatric Trials	Robert Sprague
5:15 PM	Pediatric Clinical Trials: The FDA Experience Orphan Drug – FDA	William Rodriguez/ Tan Nguyen
5:35 PM	Questions/Issues for Working Group Discussion	

5:45 PM **ADJOURN DAY 1/OVERVIEW AREAS 1-6**
Work Group leaders will hand to NIH program officers any revisions to work group discussion topics: Epidemiology; Ethical Considerations; Diagnosis/Assessment; Intervention Research; Research Design.

6:00 PM **OPENING RECEPTION - Gazebo**
Sponsored by: American Academy of Child and Adolescent Psychiatry
FRAXA Research Foundation
National Down Syndrome Society
Prader-Willi Syndrome Association

DAY 2: Friday, November 30th

8:00 AM **BREAKFAST** outside conference room

- **SESSION 7: RESEARCH TRAINING NEEDS (BUILDING THE INFRASTRUCTURE)**

8:30 AM	Introduction	James McCracken
8:40 AM	Psychiatric Training	James McCracken
8:55 AM	Pediatric and Genetics Training	Rodney Howell
9:10 AM	Psychology, Special Education, Behavioral Training	Donald Routh
9:25 AM	Developmental Cognitive Neurology	Roger Brumback
9:40 AM	Questions/ Issues for Working Group Discussion	

9:50 AM DIVIDE INTO WORK GROUP SESSIONS

Epidemiology

Diagnosis/Assessment

Ethical Considerations

Interventions Research

Research Design

Research Training Needs: Building the Infrastructure

**12:30 PM WORKING LUNCH—Breaks taken by each group
Sponsored by: The Joseph P. Kennedy, Jr. Foundation**

**5:00 PM ADJOURN DAY 2/WORKGROUP SESSIONS
Brief meeting of session leaders with organizers and NIH program staff;
Provide Discs to Logistics Coordinator, Liz Burke**

DAY 3: Saturday, December 1st

8:00 AM BREAKFAST outside conference room

**8:30 AM Workgroup Presentations/Discussions
(20 minutes presentation/10 minutes discussion)**

8:40 AM EPIDEMIOLOGY

9:10 AM DIAGNOSIS/ASSESSMENT

9:40 AM ETHICAL CONSIDERATIONS

10:10 AM INTERVENTIONS RESEARCH

10:40 AM BREAK

11:00 AM RESEARCH DESIGN

11:30 AM RESEARCH TRAINING NEEDS-BUILDING THE INFRASTRUCTURE

12:00 PM GENERAL DISCUSSION

1:00 PM CLOSING REMARKS

