

Research on Psychosocial and Behavioral Interventions in Autism: Confronting the Methodological Challenges

September 5 and 6, 2002

Neurosciences Center
Conference Room C
6001 Executive Boulevard
Rockville, Maryland

Sponsors:

National Institute of Mental Health (NIMH)
National Institute of Neurological Disorders and Stroke (NINDS)
National Institute on Deafness and Other Communication Disorders (NIDCD)
National Institute of Child Health and Human Development (NICHD)
NIH Office of Rare Diseases

Background:

In November 1999, the NIH Autism Coordinating Committee (NIMH, NINDS, NIDCD, and NICHD) and the Department of Education, Office of Special Education, sponsored a research workshop, "Treatments for People with Autism and Other Pervasive Developmental Disorders: Research Perspectives". Within that meeting, the Psychoeducational/Behavior Interventions Working Group identified research priorities related to treatment development, testing efficacy of existing treatments, further defining critical elements of effective treatments, development of treatment outcome measures, and application of effective treatments in a variety of settings. A full report of that meeting and the recommendations can be found at www.nimh.nih.gov/research/autismworkshop.cfm.

The current workshop was conceived as a format for focusing on the scientific methods and challenges specific to evaluating the efficacy of conducting research on psychosocial and behavioral interventions.

Primary Aim:

To review the state-of-the-science with regard to psychosocial, behavioral, and educational interventions for children with autism; to examine the barriers to progress in the field; and to discuss potential strategies for overcoming those barriers. To identify actions that could help move the field ahead.

Assumptions:

1. We need to be able to tailor treatments to specific subsets of children with PDD, or to specific symptom profiles.

2. There is need for a diversity of designs that inform the questions we need to answer; all should be rigorous and lead to evidence-based treatments.

3. We need to develop and/or define which outcome measures are valid and discriminating, both scientifically and clinically.

4. The intent to implement treatments in the community without loss of effectiveness must be considered from the beginning and should enter into the design of treatment studies.

Key Questions:

What is the state of the art regarding evidence-based psychosocial interventions for autism? What do we know about moderators and mediators of treatment effects?

What are some ideas for innovative techniques to meet the challenges of conducting interventions research with this population? What promising innovations are being tried, and are there ideas to be borrowed/adapted from other fields?

What are some strategies for future directions that will further the field in establishing the effectiveness in existing interventions, develop innovative interventions to fill in the gaps, and establish effective use of evidence-based practices in the field?

What are some ways that NIH can facilitate high quality research on efficacy and effectiveness of psychosocial and behavioral interventions for autism spectrum disorders?

Workshop Planning Committee:

Catherine Lord, Ph.D., *University of Michigan, Co-chair*

Peter Szatmari, M.D., *McMaster University, Co-chair*

Ann Wagner, Ph.D., *NIMH, Co-chair*

Judith Cooper, Ph.D., *NIDCD*

Deborah Hirtz, M.D., *NINDS*

Peggy McCardle, Ph.D., *NICHD*

Lisa Freund, Ph.D., *NICHD*

AGENDA

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Time

Thursday September 5

08:00 am

Registration

08:30 am

Welcome

Richard Nakamura, Ph.D., Acting Director, NIMH

Introduction of participants

Ann Wagner, Ph.D., NIMH

Deborah Hirtz, M.D., NINDS

Judith Cooper, Ph.D., NIDCD

Lisa Freund, Ph.D., NICHD

Peggy McCardle, Ph.D., NICHD

08:45 am

Introduction to the meeting aims and format

Cathy Lord, Ph.D., University of Michigan

Peter Szatmari, M.D., McMaster University

09:00 am

Update on Evidence-Based Treatment in Autism: State of the Science

What is the state of the art regarding evidence-based psychosocial interventions for autism? What are the gaps in our knowledge? What are the next steps needed to move the science ahead? Is there evidence that can be used to tailor treatment to individual children, or predict which children will respond best to a particular intervention?

Presenters:

Geraldine Dawson, Ph.D., University of Washington

Sam Odom, Ph.D., Indiana University in Bloomington

Discussion Facilitators:

Bryna Siegel, Ph.D., University of California, San Francisco

Cathy Lord, Ph.D., University of Michigan

09:45 am

Recruitment Challenges and Solutions

What are potential solutions to the recruitment challenges posed by this population (e.g., heterogeneity of the population, how to handle concurrent treatments)? What are some examples of techniques that are working? What factors should be considered during recruitment to foster cross-site replication and/or pooling of samples? What are people doing successfully to recruit from traditionally underserved populations? Is there some way of incorporating parent preferences into the study design?

Presenters:

Mike Aman, Ph.D., Ohio State University

Wendy Stone, Ph.D., Vanderbilt University

Discussion facilitators:

Marian Sigman, Ph.D., University of California Los Angeles

Lee Grossman, Autism Society of America

10:30 am

BREAK

10:50 am

Measuring Outcomes

What considerations are necessary in choosing appropriate primary outcome measures for use with this population (e.g., identifying core behaviors that might respond to treatment; measuring socially valid improvements)? What are people using successfully? What is needed? Are there instruments/techniques used in other populations that could be adapted?

Presenters:

Connie Kasari, Ph.D., University of California Los Angeles

Tony Charman, Ph.D., University College London

Discussion facilitator:

Paul Yoder, Ph.D., Vanderbilt University

11:35

GENERAL QUESTIONS AND DISCUSSION

12:00

LUNCH

01:00 pm

Methodological Challenges

Are there methodological challenges that are unique to psychosocial interventions in autism? What are the benefits/limitations of single subject v group designs? Should we/can we build potential predictor variables into research designs? How does one insure quality control, or treatment fidelity, in treatment trials? What are ways of incorporating individualized treatment goals into outcomes research?

Presenters:

Andrew Pickles, Ph.D., University of Manchester

V. Mark Durand, Ph.D., State University of New York, Albany

Don Guthrie, Ph.D., University of California Los Angeles

Discussion facilitator:

Susan Murphy, Ph.D., University of Michigan

02:30 pm

BREAK

02:45 pm

From the lab to the community; efficacy to effectiveness

What interventions have been demonstrated to be efficacious? Is there evidence that they are being used effectively in the community? What are the next steps toward wider dissemination of evidence-based treatments? When is it appropriate to start moving a treatment toward efficacy trials?

Presenters:

Sandra Harris, Ph.D., Rutgers University

Peter Szatmari, M.D., McMaster University

Discussion facilitators:

Lee Marcus, Ph.D. Division TEACCH, University of North Carolina

Evelyn Shaw, NECTAS, University of North Carolina

04:15 – 05:00 pm

General Discussion

Time

Friday September 6, 2002

08:30 am

Brief Summary of Sessions from Day 1

NIH Staff

09:15

General strategies for moving the field along

Leader: Cathy Lord, Sally Rogers

09:45 am

BREAK

10:00 am

Specific strategies and suggestions regarding recruitment, outcome measures, and methodology

Leader: Peter Szatmari

10:45 am

How can the NIH assist in facilitation of the research that is needed to fill in the gaps and further the field? What are key issues that might be addressed with a targeted RFA or future meetings? Are there inter-agency collaborations that could or should be encouraged?

Leader: Ann Wagner

11:30 am

Follow-up activities

Leader: Ann Wagner

12:00 noon

ADJOURN



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U.S. Department of Health and Human Services

