Autism Town Hall Meeting: Goals and Products

- Solicit public input on autism treatment research priorities for Strategic Plan
- Prepare summary of recommendations to IACC at May 12th meeting
- Use summary to help inform further development and refinement of the Strategic Research Plan
Who planned the meeting?

- **Organizing Committee**
  - IACC federal representatives—NIEHS, NIMH
  - IACC public members—Lee Grossman and Lyn Redwood
  - UC Davis/M.I.N.D. Institute faculty and staff

- **Other contributors**
  - IACC members
  - NIH Autism Coordinating Committee
  - Autism Speaks
  - National Autism Association
Why Sacramento?

• Geographic balance
• Critical mass of autism researchers and infrastructure
  – UC Davis/M.I.N.D. Institute
    • NIEHS/EPA-funded Children’s Center for Environmental Health and Disease Prevention
    • NIH-funded STAART Center, Autism Center of Excellence
• Active parent and advocacy communities
Meeting Format

• Introduction to Strategic Planning Process
• Series of three panel discussions
• Public comments and questions after each panel
  – Three hours devoted to open dialog
Panel Themes and Goals

• **Themes**
  – Panel I: ASD treatment in young children
  – Panel II: ASD intervention, beyond the young child
  – Panel III: Summary and Open Dialog with public

• **Common Goals**
  – Stimulate discussion about the range of treatments being used
  – Develop recommendations about research priorities including issues of efficacy and safety.
Panel I members

- **Michael Chez**, Director of Pediatric Neurology, Sutter Memorial and Sutter Neuroscience Medical Group
- **Sally Rogers**, Professor of Psychiatry and Behavioral Sciences, M.I.N.D. Institute, UC-Davis Medical Center
- **Randi Hagerman**, Professor of Pediatrics, Medical Director, M.I.N.D. Institute, UC Davis Medical Center
- **Lynne Mielke**, founder, Developmental Spectrums East Bay Medical Clinic, Pleasanton CA
- **Nancy Duley**, parent/advocate
- **Claire Bothwell**, parent/advocate
- **Lyn Redwood**, IACC public member, cofounder, coalition for SAFE MINDS
Panel I highlights

• Biomedical and psychiatric comorbidities associated with ASD—consider ASD as a multi-system disorder
• Autism Heterogeneity—need research to match symptoms with treatments
• Vaccines as risk factors
• Novel treatments with reported benefit by DAN! physicians
• Role of toxicants/xenobiotics
• Novel research approaches
• Infrastructure and capacity needs
• Training and education
Panel II members

- **Isaac Pessah**, Director, *UC Davis Center for Children’s Environmental Health and Disease Prevention*
- **Pilar Bernal**, ASD Regional Director, Kaiser Permanente, Northern California
- **Ruth Christ Sullivan**, first president, Autism Society of America; founder and first executive director, now president of Autism Services Center, Huntington, WV
- **Dena Gassner**, ASD advocate, Director, Center for Understanding, Franklin TN
- **Rick Rollens**, parent cofounder UC Davis M.I.N.D. Institute
- **Lee Grossman**, IACC public member, president and CEO, Autism Society of America
Panel II highlights

- Screening, diagnosis and assessment of ASD across the lifespan
- Multidimensional services research
- Quality of life (QOL)--better ways to measure and treatments to improve QOL
- Developmental needs of individuals with ASD across the lifespan
  - Adolescence, aging
  - Chronic biomedical conditions
- Effective supports for higher functioning individuals with ASD
  - Employment, postsecondary education
- Inclusion of individuals with ASD in priority setting
- Economic research to establish benefit
Other recommendations

- Increase capacity for service and care providers
- Enact legislation to increase funding for services
- Increase acceptance by and in the community
- Raise awareness of unique needs and concerns of higher functioning individuals with ASD, especially in areas of employment and secondary education
- Help individuals and family members to learn about and access available services
How do we use this information?

• Reinforce consumer focus and guiding principles adopted for SP
• Prioritize SP treatment initiatives
• Refine individual initiatives
  – Ensure that funding mechanisms are matched to consumer needs
• Evaluate SP progress
  – Do parents have better information about treatment choices?
  – Are clinicians able to match individuals with effective treatments?
Summary & Next Steps

• Meeting was a success
  – Excellent attendance by public (125-150)
  – Wide range of opinions expressed in a safe environment
  – Many expressed appreciation to IACC for the opportunity to be heard

• Need to build on this success
  – Consider how to sustain ongoing dialog of IACC with public