



AUTISM SOCIETY OF AMERICA

Improving the Lives of all Affected by Autism.

Interagency Autism Coordinating Committee

National Institutes of Health October 23, 2009

Summary of the IACC Services Town Hall

Meeting - July 24, 2009

Lee Grossman | President and CEO





- Autism Society's Annual National Conference of Autism Spectrum Disorders
Pheasant Run Resort, St. Charles, Illinois
- Hear public feedback on the services initiatives outlined in the IACC Strategic Plan for ASD research
- Moderated by Ellen Blackwell and Lee Grossman
- Panel included: Susan Daniels, Gail Houle, Stephen Shore, Alison Singer, Melody Stevens and Bonnie Strickland



- Estimated over 200 people were in attendance
- Not sure of how many people “listened in” or watched the webcast
- Each panelist presented on their agency’s activities
- 28 people in attendance addressed the panel (limited by time and “cold”)
- Comments represented all regions of the country, the entire lifespan and were from multiple disciplines



Question 2: How can I understand what is happening?

1. A need for research on various ASD subtypes.
2. A need to research how the use of restraint and seclusion impacts brain and emotional development.

Question 4: Which treatments and interventions will help?

1. A need for training of additional providers of Applied Behavioral Analysis (ABA) based therapies.
2. A need to validate and document the benefits of music and arts therapies.
3. A need for research to affirm the effectiveness of specific ABA therapies.
4. A need for research into comprehensive intervention programs.



Question 5: Where can I turn for services?

1. A need for more training of service providers.
2. A need for improved coordination of services among states and among government agencies.
3. A lack of services for people with Asperger's and high-functioning autism.
4. A need to make families and providers aware of available services, including families living in remote areas and those serving in the military.
5. A lack of services for non-English speaking families in Santa Barbara, California.
6. A need for toolkits for parents, teachers, and physicians involved with children who have been newly diagnosed with ASD.
7. A need for toolkits targeted at young people who wish to pursue careers as service providers for people with ASD.
8. A need for teachers to be taught to effectively include children with ASD in a mainstream classroom.
9. A need for providers trained to treat mental health issues in people with ASD.
10. A need for modification of Medicaid legislation addressing the use of restraint and seclusion of children with ASD.
11. A need for research addressing the mental and emotional health needs of families affected by ASD.
12. A need to effectively communicate information about empirically validated services (e.g. ABA-based therapies, etc.).



Question 6: What does the future hold?

1. The challenges of implementing a continuum of services for military families and transitioning adults.
2. The challenges of providing appropriate vocational skills training, including finding and retaining employment.
3. The challenges of accurately identifying and addressing family variables, such as divorce rates.