

# Analysis of the IACC Services Subcommittee Solicited Input RFI August-September 2008

## Prepared by the IACC Services Subcommittee

The purpose of this time-sensitive RFI was to seek input from Autism Spectrum Disorders (ASD) stakeholders including individuals with ASD and their families, autism advocates, State officials, scientists, health professionals, therapists, educators, and the public at large about what they considered to be high-priority issues and concerns that surrounded the services and supports for children, youth, and adults with ASD. Specifically, the RFI sought information in the following areas: education services, health and medical services (including dental), housing, transitions, employment, community inclusion, safety, older adults, finances, guardianship, and estate planning.

The RFI was posted in the NIH Guide on August 11, 2008 and responses were accepted through September 19, 2008. The electronic link to the RFI was sent to a wide range of advocacy, research, and professional organizations, IACC members, attendees of past IACC meetings, the IACC strategic planning workgroup, the NIH autism listserv, and an email distribution list from the NIMH Office of Constituency Relations and Public Liaison.

## RFI Responses

A total of 137 responses were received, coming in from all areas of the country. Individual respondents included parents or relatives of a child with ASD, individuals self-identified with ASD; professionals involved in ASD care, educators, and school staff; and researchers in ASD and other fields. Examples of organizations that responded included state autism societies; state or local departments of health, mental health, and public health; university departments; disease-specific foundations; advocacy organizations; and professional organizations. Respondents shared many personal stories and expressed a great diversity of opinions.

These comments were collated, redacted for personally identifying information, and provided to members of the Services Subcommittee for their review.

[Web link to the complete, redacted comments](#)

Analysis:

137 commenters, including several large organizations  
497 comments  
21 comments (4%) from people who self-identified with an ASD

**Note:** Number in parenthesis indicate number of comments related to the given topic.

ADULTS WITH ASD (55 comments) = 12%

Need additional housing (15 comments)  
Need to address institutionalization concerns (7 comments)  
Need to address family concerns about “when we’re gone” (6 comments)

Need less costly housing alternatives (5 comments)  
Need better diagnosis of adults, including an assessment instrument (4 comments)  
Need more research on adults w/ASD, including census (4 comments)  
Need more/meaningful day programs (4 comments)  
Need better community integration (2 comments)  
Need lifespan services (3 comments)  
Need special behavioral services  
Geriatricians need special training in older adults w/ASD  
Need more research on medical issues related to older adults w/ASD  
Need to reduce census in group homes  
Need more information on connecting families to explore housing options

COMMUNITY (54 comments) = 12%

Better community acceptance and inclusion (14 comments)  
Need better peer opportunities (6 comments)  
Better access to services in rural areas (5 comments)  
Dissemination of research findings to community settings (5 comments)  
Need for autism centers to provide 1-stop services (4 comments)  
Need to address underserved groups (3 comments)  
People w/Asperger's syndrome need additional community inclusion (2 comments)  
Bullying (2 comments)  
Need for family/unisex bathrooms (2 comments)  
Peer training/awareness (2 comments)  
Need to increase faith-based opportunities  
Need to include people w/ASD in athletic activities  
Need more play groups  
Need more community-based peer opportunities  
Need more group peer exposure v. 1:1  
Need more faith-based opportunities for peer interaction  
Need more emphasis in special peer programs (e.g. Best Buddies/Brothers-Sisters, etc.)

FAMILY SUPPORT (46 comments) = 10%

Need more respite/child care (10 comments)  
Need more family support (11 comments)  
Need crisis care opportunities (5 comments)  
Need more spousal counseling (4 comments)  
Need more family preservation counseling (4 comments)  
Need more affordable care (3 comments)  
Need more support for parents w/ASD w/children w/ASD (2 comments)  
Needed at diagnosis  
Needed for older adult parents  
Need more family support counselors w/ASD training/knowledge  
Support should address career dislocation  
Child care providers will not accept children w/ASD  
Need to approach local businesses to provide care

SCHOOL SERVICES (44 comments) = 10%

Need more teacher training/education (15 comments)

Need more adequate/appropriate services (9 comments)  
Need more funding for services (3 comments)  
Need to improve restraint issues in school settings (3 comments)  
Services need to be equally available in various regions/schools (3 comments)  
Need more knowledge in school settings regarding evidence-based services  
Need better coordination of home/school programs  
Need more therapy delivered in school settings  
Need to address non-English speaking ASD children and youth  
Need better staffing in schools  
Need more residential schools  
Need more ASD-specific programs in schools  
Need more aide training in schools  
Need more teacher-to-teacher support  
Need to provide tuition incentives to teachers interested in ASD  
Need more teachers trained to work with children and youth w/Asperger's syndrome

PROVIDERS (43 comments) = 9%

Need additional training for caregivers, staff, professionals (17 comments)  
Need better physician training (12 comments)  
Need more services/support for people with Asperger's Syndrome (5 comments)  
Need to more board-certified behavior analysts (3 comments)  
Need better training for physicians who treat adults (2 comments)  
Provider employment turnover (2 comments)  
Need providers trained in toileting issues  
Need to address low wages

INFRASTRUCTURE (41 comments) = 9%

Private insurance needs to cover people w/ASD (15 comments)  
Need better training on ASD for care coordinators (7 comments)  
Systems of care need to be coordinated (4 comments)  
Need additional care coordination (3 comments)  
Need more coordination with existing parent training centers (2 comments)  
Is crisis-driven  
Systems are underfunded  
Poor early transition  
Need more telemedicine options  
Need information to be more accessible electronically  
Require LTC insurance for all citizens  
Need better coordination between Medicare/Medicaid  
Need more ABA coverage  
Need multidisciplinary teams for care coordination  
Need more research on care coordination  
Need better information sharing between professionals  
Need Web site on ASD (e.g. information clearinghouse)

EMPLOYMENT (31 comments) = 6%

Need employment support/training (19 comments)  
Need better engagement by community employers (7 comments)

Need appropriate vocational services (3 comments)  
Need more equity  
Need study on people w/ASD and employment

#### EVIDENCE-BASED SERVICES AND SUPPORTS (27 comments) = 5%

Need more information to evaluate effectiveness and efficacy (21 comments)  
Need more information on cost-effectiveness (5 comments)  
Need more information regarding what works for people with particular ASD symptoms

#### HEALTH AND SAFETY (27 comments) = 5%

Need additional training and awareness for emergency/first responders (14 comments)  
Concerns regarding criminal justice system (5 comments)  
Need to keep people safe at home (wandering, bolting) (3 comments)  
Need to address restraint prohibition on medical care  
Need for additional research on safety  
Need to expand Project Lifesaver  
Need special Amber type alert for people w/ASD  
Need a voluntary community database of people w/ASD

#### EARLY DIAGNOSIS & TREATMENT (25 comments) = 5%

Need more and better screening (22 comments)  
Need better assessment tools  
Treatment should begin w/in 45 days  
Need more early treatment

#### TRANSITION TO ADULTHOOD (25 comments) = 5%

Need improvement and additional research (14 comments)  
Need more support for transitions to college (5 comments)  
Need more support for transitions from middle/high school (4 comments)  
Need clearinghouse on transition information  
Need more counseling for families on transition issue

#### THERAPIES (23 comments) = 5%

Need more social skills training (5 comments)  
Need more information on/more alternative therapies (4 comments)  
Need more ABA providers (4 comments)  
Need more sensory integration therapy (3 comments)  
Need more studies on types of ABA (2 comments)  
Occupational therapy needs more research  
Need more occupational therapy  
Need more speech therapy  
Need more non-aversive ABA treatments  
Need more studies on speech pathology and audiology

#### LEGAL/GUARDIANSHIP (15 comments) = 3%

Need more legal planning services (6 comments)  
Ethics issues in guardianship (4 comments)  
Need more attorney training on ASD  
Need streamlined guardianship  
Need help with estate planning  
More information on guardianship for people with ASD in particular  
Need more guardian to guardian support

DENTAL (11 comments) = 2%

Need special training for dentists (4 comments)  
Need better access to dental services (3 comments)  
Need better access to sedation (2 comments)  
Need more research on ASD and dental issues  
Need incentives to dentists who treat people w/ASD

MEDICAL TREATMENT (11 comments) = 2%

Need better information regarding what works (6 comments)  
Need more heavy metal screening (2 comments)  
Need more information on long-term effects of psychotropic medications  
Need more information on older adults and medications  
Need to address issues surrounding wait time for appointments

VACCINES (8 comments) = 2%

Need more study (4 comments)  
Focus should shift from vaccines (4 comments)

ASSISTIVE TECHNOLOGY/AUGMENTATIVE COMMUNICATION (6 comments) = 1%

Need more availability (4 comments)  
Affordability concerns  
Rapid prompting needs more evaluation

DIET (4 comments) = 1%

Need more information on diets (2 comments)  
Need more nutrition services  
Need to establish Web group on diets

OTHER (N/A) = 1%