

## **IACC Services & Support Comments: Background & Talking Points (Sept. 2008)**

**Category : Research and Data Collection**

**Published by [Admin](#) on 2008/9/15**

Background & Talking Points for IACC Request for Information on Services & Support

### **Background:**

The Interagency Autism Coordinating Committee (IACC) has put out a Request for Information (RFI) to seek input from stakeholders (those interested in autism), including autistic individuals, about what they consider to be high-priority issues and concerns surrounding services and supports for children, youth, and adults with ASD.

The RFI is due no later than Sept. 19, 2008, seven days from now.

People should direct their comments to [iaccservices@mail.nih.gov](mailto:iaccservices@mail.nih.gov) by September 19th, 2008.

More info from NIMH can be found here:

<http://grants.nih.gov/grants/guide/notice-files/NOT-MH-08-016.html>.

This RFI provides an excellent opportunity for self-advocates and allies to make our voices heard. Members of the IACC are very interested in hearing from individuals on the autism spectrum. They've heard extensively from the anti-vaccine crowd, from parents, experts, researchers, and from people on the autism spectrum.

More input from autistic adults at this point, when the IACC is coming close to finalizing a budget and mission statement for the Strategic Plan, will mean more attention to the issues we consider to be most important.

The focus of this particular RFI on services and supports is an area that many autistic adults have much to say about; here is a chance to say it directly to the committee that will be allocating resources to various areas. Currently, funding is skewed toward genetic research and research into treatments and interventions.

In the time that autistic individuals have been submitting comments and testifying at IACC meetings, some positive change has been noted in the amount of funds earmarked for research into services and supports.

It is important that the IACC hear from everyone who is able to

comment because part of the task of assessing importance is to determine the extent of the population that has an interest in the decisions that the IACC will make.

The IACC decides levels of funding for research into supports and services, but does not fund supports and services themselves.

### **Talking Points**

The Autistic Self Advocacy Network has developed these talking points to assist individuals in writing statements to IACC on the topic of supports and services.

The RFI lists a number of areas of concern that can be addressed. You do not have to address every topic. You can pick the ones that are the most important to you. Feel free to change the wording so that it reflects your most important priorities.

#### Education:

Studies need to be undertaken that assess current levels of supports and services within the public education system. When treatments and interventions that look promising are developed, additional funding must be appropriated to address implementation so that teachers, students, parents, and other education professionals are up-to-date and have access to information, training, technological resources such as AAC, and other resources.

#### Health and medical services (including dental):

Access to health and medical services, particularly for adults on the autism spectrum, is of paramount importance for research funding. Current studies that focus on diagnosis and treatment of children do not address the very real need for healthcare access for autistic adults who may not have insurance, may have communication difficulties and other difficulties that prevent them from obtaining adequate care. Education of health care professionals so that they can interact knowledgeably with autistic patients/clients is one area for research into services and supports.

#### Housing:

Research into housing alternatives, following ideas such as those in the Community Choice Act and Money Follows the Person projects, should be undertaken. Warehousing of individuals in residential centers is undesirable yet often occurs because infrastructure for other types of housing is unavailable or underutilized. Research needs to include cost-effectiveness measures, some of which are already available, which show that housing in the community costs

less than residential living.

#### Transitions:

Research into the most effective transition options needs to be undertaken. Parents and young adults on the spectrum often have nowhere to turn after they age out of the school environment. A clearinghouse of options should be researched and developed so that families will have resources already in place.

#### Employment:

Research into employment options and opportunities for people on the autism spectrum needs to include components such as accommodations, training, and career counseling. Research in other areas such as treatment, interventions, diagnosis, and genetic research, can be used to counter stereotypes of what an individual on the spectrum can do for employment. Resources for trainers, counselors, employers, and others need to be developed so that autistic people are not discriminated against in the employment world because of stereotypes and misunderstanding. The IACC and NIMH can set the tone for accurate information that can help employers assess individual strengths and weaknesses rather than relying on discriminatory assumptions.

#### Community inclusion:

Full inclusion in the community needs to be examined and research initiatives should focus on this very important aspect of adult life, and life for children who will grow into adulthood. Community-based participatory research should be implemented that will accurately reflect the actual needs of the autistic teen and adult population.

#### Safety:

Research into areas that can improve safety for autistic people, throughout the lifespan, and in different situations, needs to be undertaken. Areas to focus on are keeping people on the autism spectrum safe if they have a tendency to wander, or do not understand dangerous situations. Education of parents, professionals, first responders, and autistic people should be undertaken, and the best methods for ensuring safety should be addressed by research in this area. Sometimes autistic people can appear unusual in behavior, which will attract attention from law enforcement and other personnel. Training for professionals in aspects of autistic behavior that might not be understood is a crucial area to address in order to promote the safety of all.

#### Older adults:

Many older adults remain undiagnosed. Some have no health insurance. Some are living in poverty or are homeless. Many older autistic adults will need medication, including medication for health problems. Research into how to best reach out to older adults who may not have an autism diagnosis but may present as in need of services should be undertaken. Research into the effect of common medications, including for non-autistic-related health problems such as diabetes, should be undertaken. Because of the possibility of extrapyramidal or paradoxical drug reactions, and the general effect of certain drugs on older people, cases should be documented so that any adverse pattern of reaction can be established. Housing, health care, dental care, and community inclusion should all be addressed and tailored to the older autistic population. Community-based participatory research can be invaluable in determining the best ways to access health and other care.

#### Finances:

Across the lifespan, autistic children and their families, autistic adults and elders will have various financial needs. Research into how to help families and individuals on the spectrum cover the costs associated with treatments and interventions, and a clearinghouse for resources should be developed. In addition, financial resources for autistic adults who have difficulty with financial concepts should be researched and implemented.

#### Guardianship:

Research into the best ways to establish guardianship should be undertaken, including autistic adults as full participants in the research process in order to establish the most ethical procedures for guardianship. Guardianship should be tailored to the needs of the individual rather than being a one-size-fits-all category, since some individuals will need guardianship in limited areas, but not all aspects of their lives.

#### Estate planning:

Families with autistic individuals need to take extra precautions in planning an estate, especially for individuals who may need ongoing care throughout life. Autistic adults also may need assistance with estate planning. Research leading to the development of estate planning tools that can assist families and autistic individuals in making sound decisions should be initiated.

Ari Ne'eman  
President  
The Autistic Self Advocacy Network  
1660 L Street, NW, Suite 700

Washington, DC 20036

<http://www.autisticadvocacy.org>

732.763.5530