



**AUTISM SPECTRUM DISORDERS (ASD) SERVICES AND SUPPORTS
RECOMMENDATIONS**

Presented to

Interagency Autism Coordinating Committee Services Subcommittee

February 24, 2009

Acknowledgements

ASD Services and Supports Recommendations were developed by the Services Subcommittee of the Interagency Autism Coordinating Committee in _____, 2009. The Services Subcommittee is comprised of the following members of the Interagency Autism Coordinating Committee:

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Introduction

The number of people diagnosed with ASD is a growing and urgent concern for families, service providers, and policymakers, as the nation's existing health, education, and social service systems strive to respond to their needs in a comprehensive manner. Though a number of effective services and funding options for individuals with ASD exist, they are often scattered, fragmented, and poorly coordinated. There are no widely accepted service guidelines for ASD services and supports, and there are significant gaps in knowledge about ASD among providers. Where services are available, financing mechanisms are often inadequate to meet needs. The success and well being of people with ASD and their families are affected by their communities and resources.

The Interagency Autism Coordinating Committee (IACC) has been established in accordance with the Combating Autism Act (CAA) of 2006 ([P.L. 109-416](#)). On March 14, 2008, the IACC established its Services Subcommittee. The Services Subcommittee includes government and public members of the IACC, and operates according to Federal Advisory Committee Act rules.

The mission statement of the Services Subcommittee is:

To assess and improve services and supports for people with ASD

The vision statement of the Services Subcommittee is:

All people with ASD have the services and supports they need and desire throughout the lifespan to lead productive lives in the community and to reach their fullest potential

In developing its first Strategic Plan for Autism Spectrum Disorder Research, issued on January 26, 2009 the IACC included as its foundation a series of six critical questions asked by people and families living with ASD:

- *When should I be concerned?*
- *How can I understand what is happening?*
- *What caused this to happen and can it be prevented?*
- *Which treatments and interventions will help?*
- *Where can I turn for services?*
- *What does the future hold?*

The two last chapters of the Strategic Plan (listed above) have the following associated Aspirational Goals:

Interventions will be developed that are effective for reducing both core and associated symptoms, for building adaptive skills, and for preventing the disabilities associated with ASD, and;

Communities will implement high quality, evidence-based and cost-effective services and supports across the lifespan for people with ASD.

The IACC adopted a set of Core Values to be used in development and implementation of its Strategic Plan:

- *Sense of Urgency*
- *Excellence*
- *Spirit of Collaboration*
- *Consumer-focused*
- *Partnerships in Action*
- *Accountability*

The Strategic plan also identifies a number of Cross-Cutting Themes that emerged repeatedly as it engaged with stakeholders during its development:

- *Heterogeneity*
- *Prevention*
- *Earlier Detection*
- *Lifespan Perspective*
- *Data-Sharing*
- *Resources*
- *Public-Private Partnerships*
- *Community Engagement in ASD Research*

These Core Values and Cross-Cutting Themes also overlay development of the ASD Services and Supports Recommendations.

In January 2009 President Obama and Vice-President Biden published their four-part plan to empower individuals with disabilities in order to equalize opportunities for all Americans. The last part of the plan makes special note of people with ASD, emphasizing services and supports:

*“First, provide Americans with disabilities with the **educational opportunities they need to succeed** by funding the Individuals with Disabilities Education Act, supporting early intervention for children with disabilities and universal screening, improving college opportunities for high school graduates with disabilities, and making college more affordable. Obama and Biden will also authorize a comprehensive study of students with disabilities and issues relating to transition to work and higher education.*

*Second, **end discrimination and promote equal opportunity** by restoring the Americans with Disabilities Act, increasing funding for enforcement, supporting the Genetic Information Nondiscrimination Act, ensuring affordable, accessible health care for all and improving mental health care.*

*Third, **increase the employment rate** of workers with disabilities by effectively implementing regulations that require the federal government and its contractors to employ people with disabilities, providing private-sector employers with resources to accommodate employees with disabilities, and encouraging those employers to use existing tax benefits to hire more workers with disabilities and supporting small businesses owned by people with disabilities.*

*And fourth, **support independent, community-based living** for Americans with disabilities by enforcing the Community Choice Act, which would allow Americans with significant disabilities the choice of living in their community rather than having to live in a nursing home or other institution, creating a voluntary, budget-neutral national insurance program to help adults who have or develop functional disabilities to remain independent and in their communities, and streamline the Social Security approval process .*

Autism

President Obama and Vice President Biden are committed to supporting Americans with Autism Spectrum Disorders (“ASD”), their families, and their communities. There are a few key elements to their support, which are as follows:

- First, President Obama and Vice President Biden support increased funding for autism research, treatment, screenings, public awareness, and support services. There must be research of the treatments for, and the causes of, ASD.*
- Second, President Obama and Vice President Biden support improving life-long services for people with ASD for treatments, interventions and services for both children and adults with ASD.*
- Third, President Obama and Vice President Biden support funding the Combating Autism Act and working with Congress, parents and ASD experts to determine how to further improve federal and state programs for ASD.*
- Fourth, President Obama and Vice President Biden support universal screening of all infants and re-screening for all two-year-olds, the age at which some conditions, including ASD, begin to appear. These screenings will be safe and secure, and available for every American that wants them. Screening is essential so that disabilities can be identified early enough for those children and families to get the supports and services they need.”*

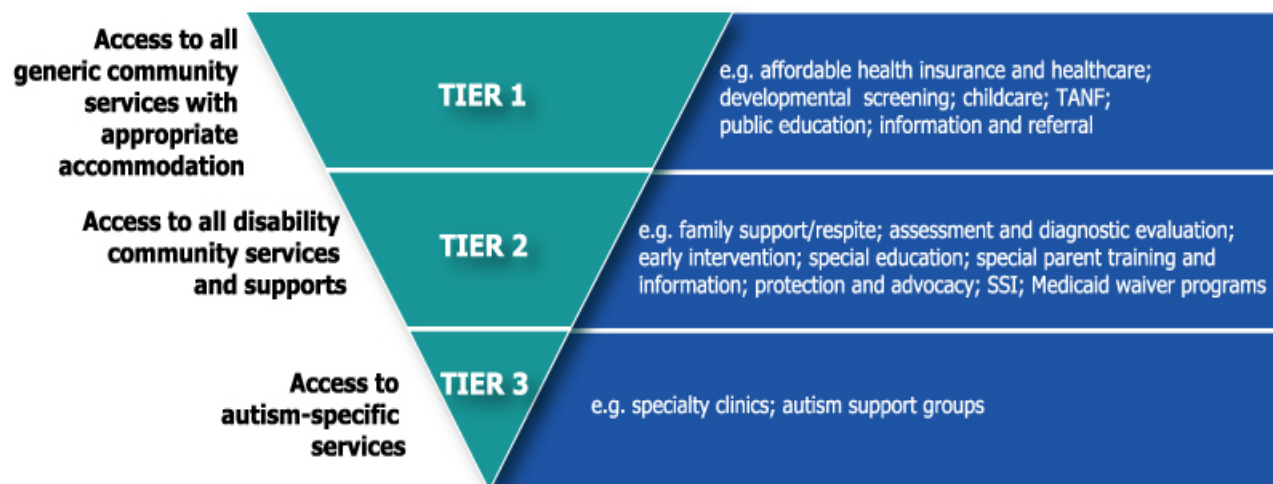
In May of 2005, the IACC approved the “Autism Spectrum Disorders Roadmap,” developed by its Services Subcommittee, intended to provide a national blueprint to enhance existing systems; expand services for children, youth, and adults with ASD and their families; and coordinate services across systems. The Roadmap was built around the six performance measures for community systems of service outlined in the New Freedom Initiative (NFI), a nationwide effort to remove barriers to community living for people of all ages with disabilities and long-term illness. The NFI supports States' efforts to meet the goals of the *Olmstead v. L.C.* Supreme Court decision issued in July 1999, that requires States to administer services, programs, and activities "in the most integrated setting appropriate to the needs of qualified individuals with disabilities." The performance measures included in the Roadmap are:

- family and professional partnerships;

- early and continuous developmental and medical screenings;
- availability of all needed health, education, and social services;
- organization of community-based services for easy use;
- effective youth transition to adult services, work, and independence;
- access to adequate public/private insurance or other financing mechanisms.

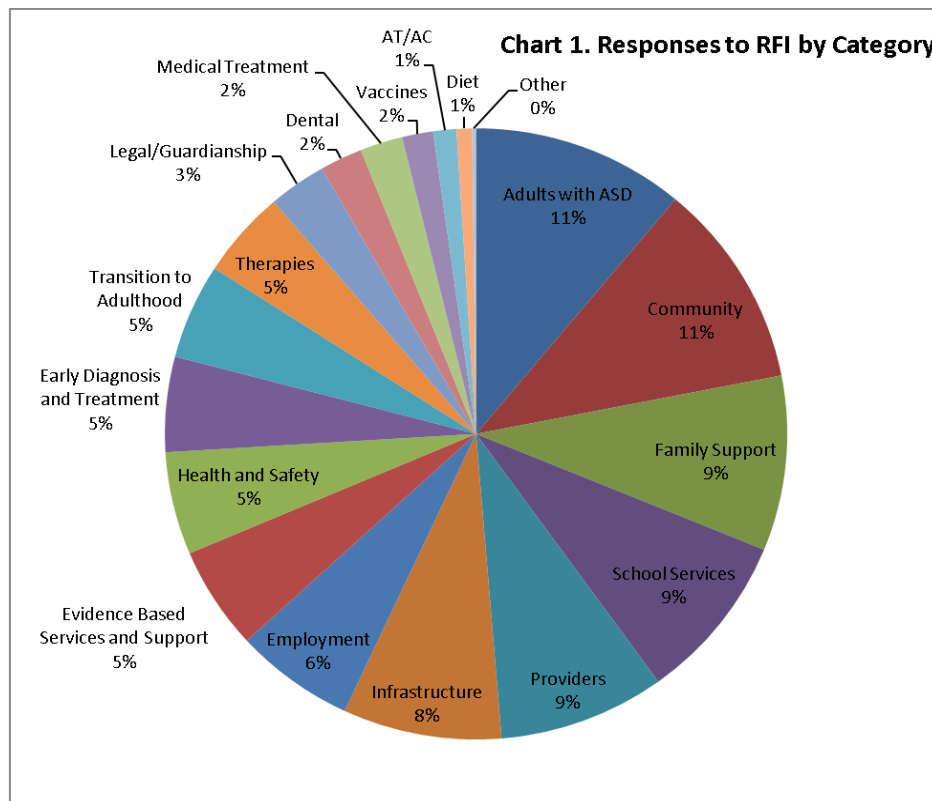
The Roadmap also illustrated a model that assured people with ASD have access to the broad range of community services, including those available to all, to people with disabilities and chronic conditions, and to services that are uniquely required to address ASD.

FIGURE 1



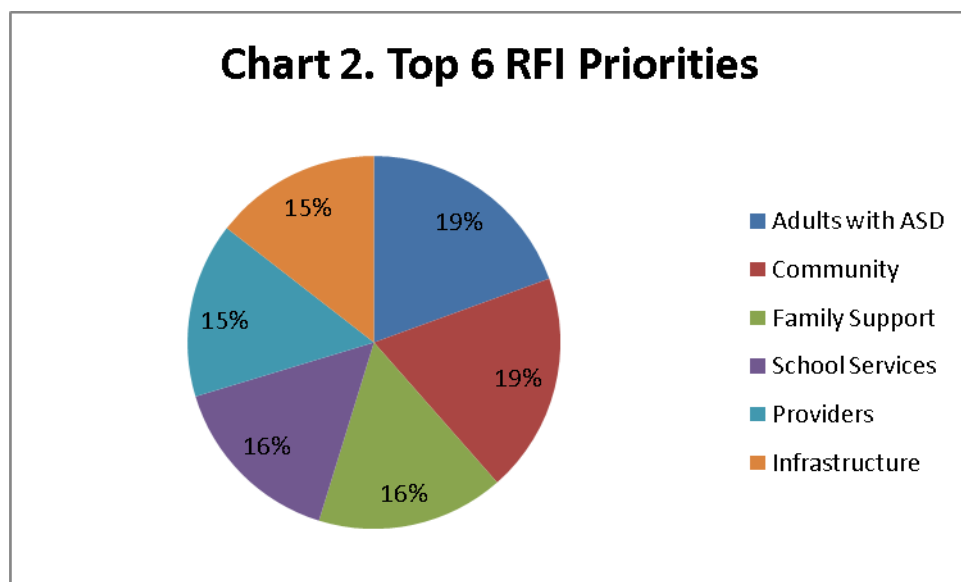
In August 2008, the Services Subcommittee sought input from ASD stakeholders including individuals with ASD and their families, autism advocates, State officials, scientists, health professionals, therapists, educators, and the public at large about what they considered to be high-priority issues and concerns surrounding services and supports for children, youth, and adults with ASD. The Subcommittee viewed the RFI as a next step to obtain updated information about present and future services and supports to individuals with ASD, and their families, across the lifespan. A Request for Information (RFI) was issued (NOT-MH-08-016) by the National Institute of Mental Health, and 137 commenters responded, including people who self-identified with ASD (4 percent of the comments), advocacy organizations, family members, physicians, and other professionals. (See Chart 1.)

The 137 responses received can be divided into the 18 categories depicted in the



Of nearly 500 comments, the following six categories emerged as stakeholder priorities (see Chart 1.):

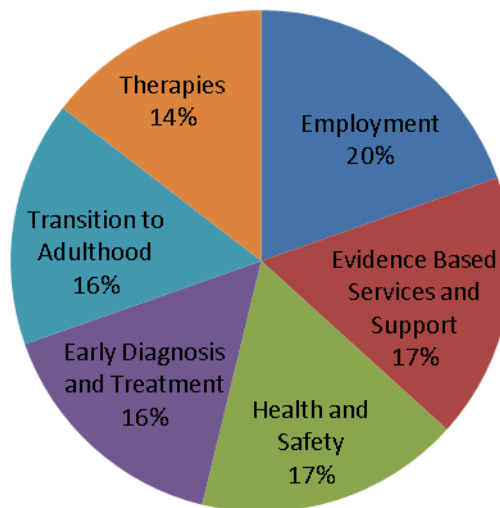
1. Adults with ASD
2. Community
3. Family Support
4. School Services
5. Providers
6. Infrastructure



Emergent categories are:

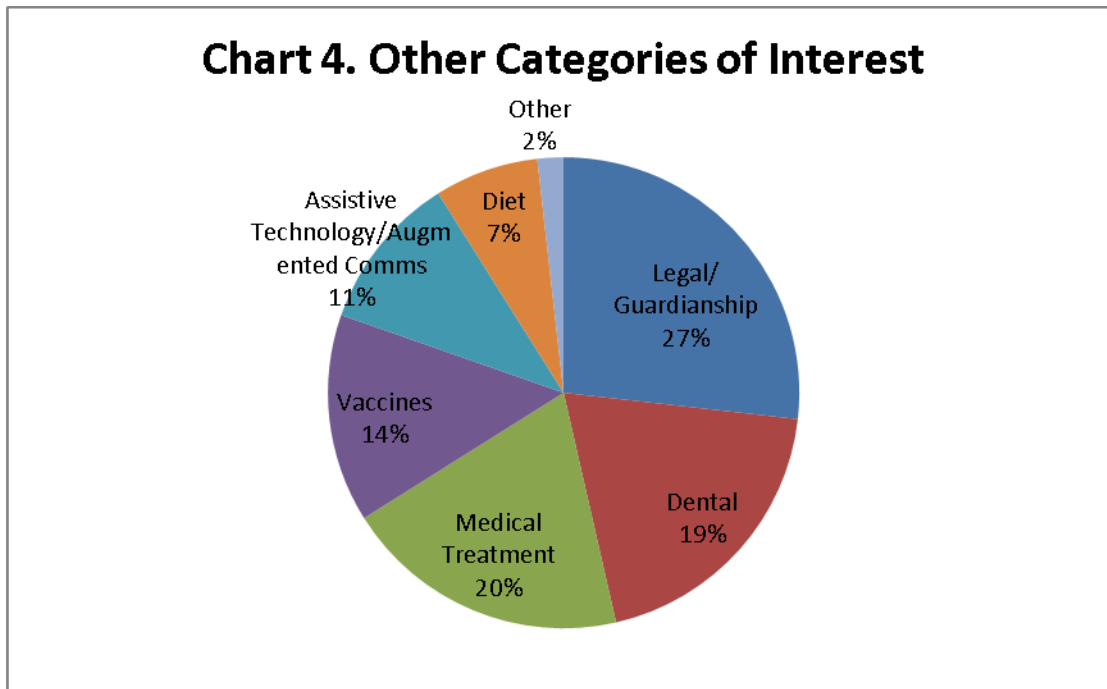
7. Employment
8. Evidence-based Services and Supports
9. Health and Safety
10. Early Diagnosis and Treatment
11. Transition to Adulthood
12. Therapies

Chart 3. Emergent Priorities



Other categories of interest within the RFI are:

- 13. Legal/Guardianship
- 14. Dental
- 15. Medical Treatment
- 16. Vaccines
- 17. Assistive Technology/Augmentative Communication
- 18. Diet



Consistent with the IACC's commitment to public input, and the spirit of the CAA, the Subcommittee will focus its efforts on identifying one goal, challenge, and recommendation for each of the identified priority recommendations.

The Services Subcommittee will issue a second RFI to solicit additional input from stakeholders regarding this plan, and the initially identified eighteen categories of concern.

Adults with ASD – GOAL/CHALLENGE/ RECOMMENDATION

Community – GOAL/CHALLENGE/RECOMMENDATION

Family Support– GOAL/CHALLENGE/RECOMMENDATION

School Services – GOAL/CHALLENGE/RECOMMENDATION

Providers – GOAL/CHALLENGE/RECOMMENDATION

Infrastructure – GOAL/CHALLENGE/RECOMMENDATION