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# AUTISM SOCIETY OF AMERICA

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Improving the Lives of all Affected by Autism.

## **Autism and Public Policy in America: *The Case for Systems Change***

OSEP National Early Childhood Conference

Arlington, VA. | December 8, 2009

Lee Grossman | President and CEO





**The Autism Community =  
10s of Millions**

**GROWING and affecting  
all in our society**



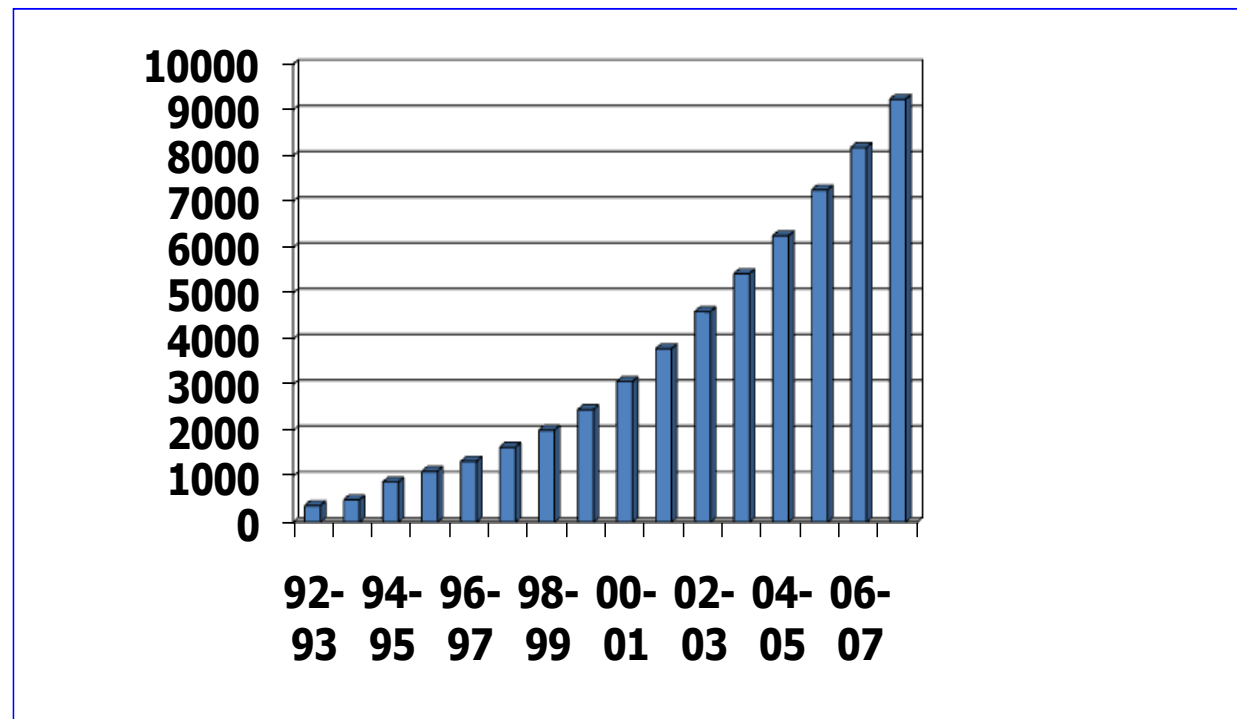
# Autism Facts

- **1 in 91** births...
- **Over 1 to 1.5 million** Americans...
- **Approximately 12.5-17 million** family members
- **Fastest-growing developmental disability -- rate → 10 - 17 %**
- **Growth comparison during the 1990s**
  - **U.S. population increase: 13%**
  - **Disabilities increase: 28.4%**
  - **Autism increase: 1,354 %**
- **US \$90 billion** annual health care cost
  - **90% of costs are in adult services**
- **Cost of treatment can be reduced by 2/3 with early diagnosis and intervention**
- **In 10 years, the annual cost will be \$200-400 billion**



## Number of Students Identified with Autism Spectrum Disorders in Indiana's Public Schools

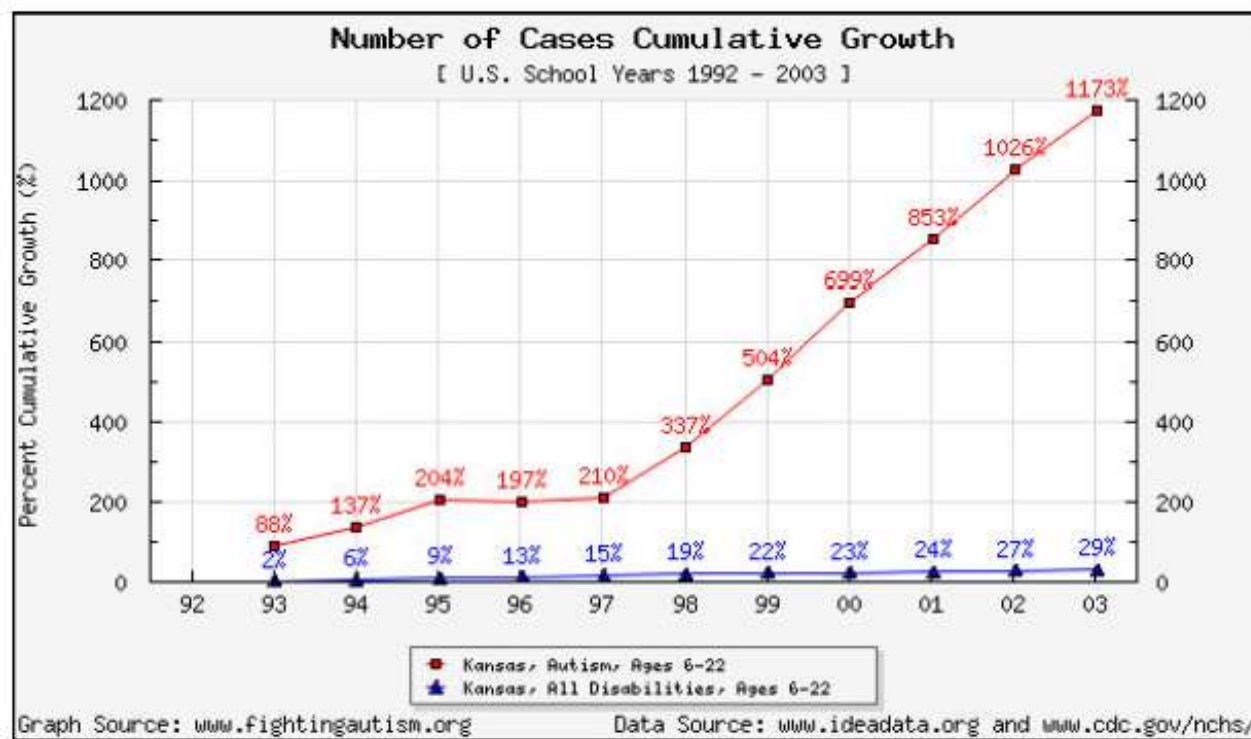
(Source: Indiana DOE- Federal Unduplicated Child Count)



State ID Rate (2007-08): 1/113

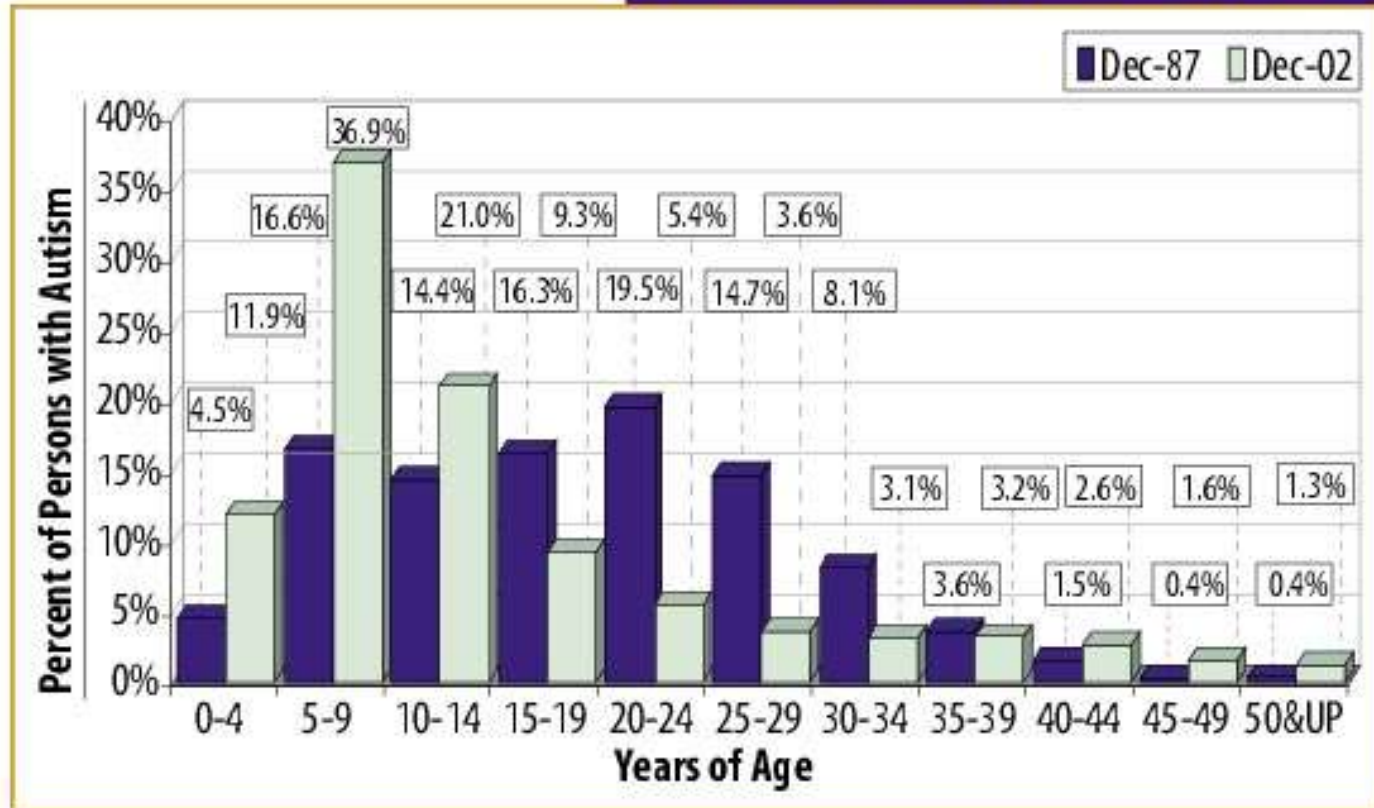


# Cumulative Growth of Number of Students with Autism 1992 - 2003



# A tidal wave is coming...

**Figure 7 - Age Distribution for All Persons with Autism (Codes 1 & 2) in 1987 and 2002**





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**Autism is a social, economic  
and health crisis.**

**Autism is a national  
emergency.**



# Autism is an EPIDEMIC



**Autism is:**

**Genetically based,  
neurological condition**

**[http://www.waisman.wisc.edu/cedd/  
guidelines/pdf/Autism\\_Flip.pdf](http://www.waisman.wisc.edu/cedd/guidelines/pdf/Autism_Flip.pdf)**



- **Complex Spectrum Disorder**
- **Developmental Disability**
- **Neurological Disorder**
- **No racial, ethnic, or social boundaries**
- **Social interaction, communication skills and the senses impacted**
- **No known cause or cure**
- **No known singular effective treatment modality**



# The Realities of Autism

- **Complex disorder**
- **Unique research and therapeutic interventions needed**
- **Multifaceted and multi-agency approach**
- **Lifespan needs**
- **Population dramatically increasing**
- **Economic and social crisis**
- **Autism is Treatable**



## Federal Government's Response

- **Children's Health Act of 2000**
- **NIH – Research and Autism Centers of Excellence**
- **CDC - Data collection on prevalence and characteristics**
- **HHS – ACF, CMS, and HRSA**
- **Interagency Autism Coordinating Committee**



## Federal Service Programs

- **Individuals with Disabilities Education Act**
  - Early intervention and preschool services
  - Special education and related services
- **Rehabilitation Act**
  - Job training and employment services
- **Maternal and Child Health Block Grant**
  - Health services for children with special needs
- **Medicaid waiver services**
  - Health and independent living supports



## **2008 Federal Policy Activities**

**Combating Autism Act**

**Amendment to the Defense Authorization Act**

**Expanding the Promise for Individuals with  
Autism Act**

**Teacher Education for Autistic Children Act**

**Empowering Children with Autism through  
Education Act**

**Global Autism Assistance Act**

**Fairness in Autism Treatment Act**

**Helping HANDS for Autism Act**



# Autism Spectrum Disorder Services Roadmap

<http://www.nimh.nih.gov/autismiacc/asdroadmap.pdf>



**The increased number of children and adults diagnosed with ASD is a growing and urgent concern for families, service providers, and policy-makers, as the nation's existing health, education, and social service systems struggle to respond to the service needs of this population in a comprehensive manner.**

**Although a number of effective services and funding options for individuals with ASD exist, they tend to be scattered, fragmented, and poorly coordinated.**



**There are no widely accepted or implemented service guidelines for ASD, and there are significant gaps in knowledge about ASD among the professionals serving these individuals.**

**Even where services are available, public and private financing are often inadequate to meet the needs of most individuals with ASD and their families.**



**The success and well being of individuals with ASD and their families are affected by, and in large part, depend on communities and their resources.**

**Thus, we must respond by developing community systems that are integrated across service sectors and are collectively responsible for achieving appropriate individual, family, and community outcomes.**



# A Dramatic, Proactive, Aggressive and Coordinated Response from Multiple Federal Agencies



# COMBATING AUTISM ACT

**On December 19, 2006, President Bush signed the landmark Combating Autism Act of 2006 (CAA). This critical legislation recognized autism as a national public health priority, and authorized a significant increase in funding for autism research, diagnosis and early intervention. In all, this legislation provided for almost \$1 billion for autism related activities at the National Institutes of Health, the Centers for Disease Control and Prevention, the Health Resources and Services Administration, and other federal agencies.**



## **Expanding the Promise for Individuals with Autism Act of 2007**

- **Treatments, Interventions, and Services Evaluation Task Force**
- **Demonstration Grants for Coverage of Treatments, Interventions, and Services**
- **Planning and Demonstration Grants for Services for Adults**
- **Expanding Access to Post-diagnosis Care**
- **GAO Study On Service Provision and Financing**
- **Emerging Needs Protection and Advocacy Program**
- **National Technical Assistance Center**



## State Activities in Autism

- **State Agency Task Forces**
- **Private Insurance legislation**
- **Teacher training and supports**
- **Medicaid waivers**
- **First responders training**



# Model State Legislation

[http://www.autismsociety.org/site/DocServer/ASA\\_MODEL\\_INS\\_LEGISLATION.pdf?docID=11961](http://www.autismsociety.org/site/DocServer/ASA_MODEL_INS_LEGISLATION.pdf?docID=11961)

**Medically necessary**

**Treatment for autism spectrum disorders**

**Behavioral treatments and interventions**

**No Exclusion Based Upon ASD Diagnosis**

**Coverage**



## Where We Need To Be

- **Expansion of C.A.R.E.**
- **Treating the Medical Aspects of Autism**
- **Environmental Concerns and Neurotoxicology**
- **Adult Issues being Addressed**
- **Psychosocial and Behavioral Interventions**
- **Continued and Growing Awareness**
- **Focus on Services and Interventions**
- **The Autism Community Coming Together**

## Estimated Number of Individuals with Autism in Selected Asian Nations and the U.S., 2007



COUNTRY	NUMBER	DATA SOURCE
<b>China</b>	<b>2,500,000</b>	University of Beijing estimate – working with Johns Hopkins to get a better number
<b>India</b>	<b>2,000,000</b>	Reports from parent groups not confirmed by government (number attempted to be verified by ASA)
<b>United States</b>	<b>1,200,000</b>	Centers for Disease Control ADDME Study 2007
<b>Indonesia</b>	<b>350,000</b>	Estimated by Health Minister of Indonesia
<b>Japan</b>	<b>300,000</b>	Widely reported to have the highest rate of autism in the world
<b>Philippines</b>	<b>250,000</b>	Estimate by the Autism Society of the Philippines – a reliable source
<b>Vietnam</b>	<b>200,000</b>	Unreliable number
<b>Thailand</b>	<b>180,000</b>	Estimate of the Minister of Mental Health



# The Environment

**Reasonable attention has been focused on the possibility of neurotoxicants and/or environmental health concerns as culprits in damaging the gene construct and “triggering” the symptoms known as ASD.**





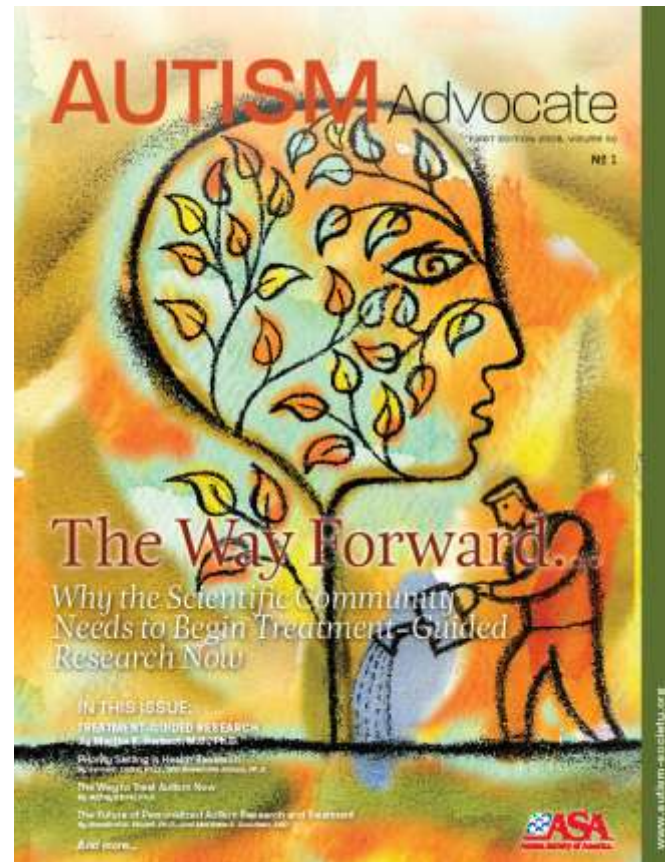
## The Environment

**Factors contributing to climate change and global warming are also the same factors contributing to the rise in Autism**



# Treatment Guided Research Initiative (TGRI)

- **Identifying environmental contributors**
- **Providing pragmatic solutions**
- **Developing the identification of final common pathways, injury interventions and improvement**



Autism Society of America *Improving the Lives of All Affected by Autism.*





**When treating, do no harm**

**To not treat may be doing the  
GREATEST HARM**



## Whole Body Condition

**Prediction**  
**Prevention**  
**Reversal**



## Where We are Today

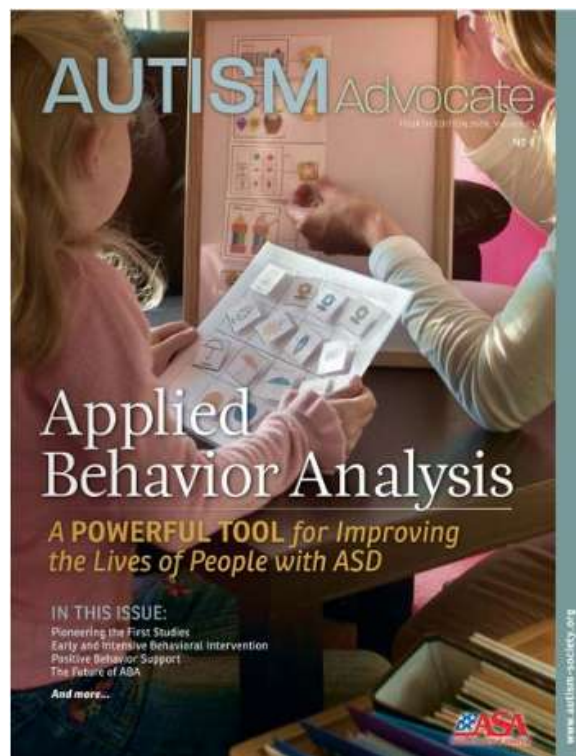
**We know what we need to know  
about autism...**

**~ the issue is accessibility.**

**There is enough information on evidence-  
based to apply now.**



# ASA Resources



[http://www.autism-society.org/site/PageServer?pagename=autismadvocate\\_aba](http://www.autism-society.org/site/PageServer?pagename=autismadvocate_aba)

Autism Society of America *Improving the Lives of All Affected by Autism.*





# GROWING UP Together

Our world is made  
Each one of us is  
much alike. We  
and have

Children with autism may look like other kids, but if you meet them you would find they are different in some ways. It may be hard for them to play, to make friends or to learn new things. Some may have trouble talking or understanding what people say. Some may talk too much about a favorite topic. But, just like you, children with autism are very special in many ways. They have families who love them very much, they go to school, and they have special interests.

This booklet is about people you may meet who have autism and how you can be their friend.

**What is Autism?**  
Autism affects the person's brain and works. It is not a and is not contagious. Some children cannot catch on to a classroom or fit in with other children. Some children have a hard time making friends, or directions. However, families, and this is easier to learn in

**How Do Kids Learn?**  
Children with autism have difficulties with strengths in other areas. Some children may be a math whiz. Some children may be a words whiz. Some children may be a words whiz. Some children may be a words whiz. Some children may be a words whiz.

## ASA'S LIVING WITH AUTISM

### Moving from PRESCHOOL TO KINDERGARTEN

**CONSIDER:**  
Special Language Consultant  
Autism Resource Center for Autism  
This material was developed with support and participation from The National Resource Center for Positive Psychology, Research and Evaluation

**PLANNING FOR EXITING PRESCHOOL AND NEW RELATIONSHIPS**  
Leaving preschool to enter a more formal educational system represents a major transition for every parent and child. The environment will be new, challenges will be different and parents of naturally gifted children will represent a

**ASA**  
Autism Society of America

# The PUZZLE of Autism

nea  
NATIONAL EDUCATION ASSOCIATION

ASA  
Autism Society of America

National Education Association



## The Obama Administration

<http://www.whitehouse.gov/agenda/disabilities>

- **Improving life-long services for people with ASD for treatments, interventions and services for both children and adults with ASD.**
- **Increased funding for autism research, treatment, screenings, public awareness, and support services.**
- **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.**
- **Universal screening of all infants and re-screening for all two-year-olds.**



## ASA's Public Policy Platform

**Human Rights**  
**Quality of Life**  
**Systems Change**



# Human Rights

- **Systematically discriminated and subjected to global abuses**
- **Moral and ethical obligation**
- **Can no longer accept that this is hopeless**
- **Must demand that action be taken now**
- **Most compelling issue of our time**



# Quality of Life

- **School inclusion**
- **Friendship/social connection**
- **Health and wellbeing**
- **Academic success**
- **Autonomy**
- **Supported and independent living**
- **Supported, independent employment**
- **Subjective wellbeing**
- **Recreation/leisure**

# Quality of Life



**ASA will continue to Support the *Autism Treatment Acceleration Act*, the *Expanding the Promise to Individuals with Autism Act* and initiatives to produce and pass a comprehensive piece of legislation that deals with creating and enhancing appropriate autism services and treatments.**

- **Provide adults the services they need to lead a productive and meaningful life.**
- **Treatments, Interventions, and Services Evaluation Task Force**
- **Provide grants for Coverage of Treatments, Interventions, and Services**
- **Provide grants for Services for Adults**
- **Expanding Access to Post-diagnosis Care**
- **Provide training Initiatives on Autism**
- **GAO Study On Service Provision and Financing**
- **Provide Emerging Needs Protection and Advocacy Program**
- **Create a National Technical Assistance Center**
- **ERISA Reform**



# The Purpose of Special Education (IDEA)

To ensure that all children with disabilities have available to them a free appropriate public education that emphasizes special education and related services designed to meet their unique need and prepare them for further education, employment, and independent living

§300.1 (emphasis added)

# Quality of Life



**ASA will continue to take a proactive role in the following legislative priorities:**

- **Teacher Education for Autistic Children Act (TEACH Act**
- **Helping Hands for Autism Act**
- **State autism insurance reform legislation**
- **Department of Defense autism related funding initiatives**
- **Community Living Assistance Services and Supports Act**
- **Community Choice Act**
- **Global Autism Assistance Act & Human Rights initiatives**
- **Disability Savings Accounts**
- **UN Global Autism Awareness Day**



## Systems Change

- **expand access to treatments, interventions, and services**
- **multi-agency, intensive, comprehensive, and evidence-based treatments, interventions and services**
- **No delay in receiving services that can improve quality of life**



# Systems Change

**The 111th Congress must:**

- **Expand, modernize, and, where appropriate, maintain national policies that provide individual supports. Such supports should encourage individual control of services, self-sufficiency, and personal responsibility among our constituents. Such services and supports must be:**
  - **consumer controlled;**
  - **family centered and culturally responsive;**
  - **based upon individual and family needs;**
  - **inclusive of personal assistance services;**
  - **easily accessible and flexible to meet the changing needs of the individual and family; and**
  - **community based.**



# Systems Change

- **Comprehensive Health Care Reform**
- **MEDICAID and Long Term Community Services and Supports**
- **Employment, Training, and Wages**
- **Housing**
- **Family Support**



## Where we go from here...

- **Human rights identifies the problem**
- **Quality of life is the goal**
- **Systems Change is how we get there.**



# Creating Opportunities

# Maximizing Potential

# Improving the Quality of Life



## The Goal

**Autism, in the next  
generation, will  
become an accepted  
part of the human  
condition**



# Improving the lives of all those affected by Autism

Autism Society of America *Improving the Lives of All Affected by Autism.*





# Autism Society of America

[www.autism-society.org](http://www.autism-society.org)