Autism:
The Federal Effort

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The Inter-Agency Autism Coordinating Committee

NIH (NIMH, NICHD, NINDS, NIEHS, NIDCD)

CDC (Agency for Toxic Subst, NCBDDD)

Research

SAMHSA
HRSA
FDA
Center for Medicare Medicaid Services
Agency for Healthcare & Res Quality
Admin for Children and Families

Services

Dept of Education

Public members

Annual report to Congress: www.nimh.nih.gov/autismiacc

The Inter-Agency Autism Coordinating Committee - Research

NIH (NIMH, NICHD, NINDS, NIEHS, NIDCD) - $99M

- Genetics, Etiology, Pathophysiology, Therapeutics
- Centers – CPEA, STAART, CHARGE

CDC (Agency for Toxic Subst, NCBDDD) - $16M

- Epidemiology, Public awareness campaign
- Centers – CADDRE – 5 sites for surveillance and epi
- Information clearinghouse

Shared Resources:

- Genetic repository
- Tissue repository
- NDAR

A Strategic Plan for Autism Research

- Characterize the phenotype
- School and community interventions
- Epidemiological studies
- Early intervention/screening
- Specific treatments
- Neurobiology
- Environmental factors

	1-3 years	4-6 years	7-10 years
HIGH	**1. Peripheral biomarkers (e.g. gene expression assays) developed to provide the biological characterization (i.e. phenotype) of autism** **2. Efficacy established for drug treatments that target symptoms associated with autism**	1. Individual characteristics that predict response to behavioral and drug treatments are identified 2. Susceptibility genes and animal models of autism are identified for further study of phenotypic characteristics of autism 3. Environmental factors (e.g. viruses, medications, lifestyle factors, environmental chemicals) that contribute to the development of autism and their associated developmental windows identified	**1. 25% of cases of autism prevented through early identification and early treatment** **2. Methods developed and implemented to allow 90% individuals with autism to develop speech** **3. Genetic and non-genetic causes of autism and their interactions identified** **4. Efficacious drug treatments that target core symptoms of autism developed**
MEDIUM	**1. Resources established for genotype/phenotype studies (i.e. bioinformatics, genetic repository)** **2. Existing data studied to begin to characterize the autism phenome, as part of the larger Phenome Project** **3. Infrastructure, such as enhanced brain acquisition, established for neuropathological investigations, to identify the neuropathology of autism** **4. Technology and infrastructure developed for multi-site *in vivo* imaging studies, to identify the neuropathology of autism** **5. Randomized clinical trial developed for the evaluation of strategies for early intervention**	1.Biological and/or behavioral markers identified to develop indices of risk for the development of autism 2. Multi-site randomized clinical trial implemented to identify effective ingredients (e.g. dose, intensity, mode of delivery, age of onset) of early intervention treatments 3. Intervention methods for infants and toddlers developed, to lower the age for which there are efficacious interventions 4. Neuropathology of autism characterized, to identify brain structures and functions associated with autism 5. Developmental time course characterized for alterations in brain structures and connections in autism	**1. Feasible, sensitive autism screening method for young infants developed** **2. Pathophysiology of autism defined** **3. Treatment algorithm for autism developed, to provide guidance for practitioners and educators**
LOW	**1. Autism Phenome Project defined and planned** **2. Outcome measures improved, to enhance their effectiveness in evaluating treatment studies** **3. Twin resource developed, to study heritibality and environment factors influencing autism** **4. Innovative intervention strategies developed to improve outcome in the school and community settings throughout the lifespan, including transitions (e.g. academic functioning, social and adaptive behavior, family functioning, employment) in collaboration with the Department of Education** **5. Research Communication Network (both local and national) developed to disseminate findings among researchers and the public to increase ongoing communication**	1. Multi-site longitudinal study of subsequent pregnancies and infant siblings of children with autism implemented, to identify risk factors, broader phenotype and early characterization of autism 2. Neural circuitry and neurochemistry defined for several functions impaired in autism 3. Innovative intervention strategies evaluated to improve outcome in the school and community settings throughout the lifespan, including transitions (e.g. academic functioning, social and adaptive behavior, family functioning, employment) in collaboration with the Department of Education 4. First-generation, intensive, community-based prevalence studies with clinical evaluations implemented, to have initial data for detecting changes in prevalence of autism	**1. Longitudinal follow-up of early intervention randomized clinical trial implemented** **2. Appropriate efficacious interventions implemented for school and community settings, throughout the lifespan, including transitions (e.g. academic functioning, social and adaptive behavior, family functioning, employment) in collaboration with the Department of Education** **3. Second-generation, intensive, community-based prevalence studies with clinical evaluations planned and implemented.**

Low/Med Risk – Short Term

1. **Autism Phenome Project**
   MIND Institute pilot, Intramural NIMH

2. **Early screening/detection tools**
   CPEA and CDC

3. **Genetic repository**
   1100 fam and sib-pairs samples, 1117 affected sibs, 674 independent cases, 1286 controls

4. **Clinical trials network**
   Two trials underway (300 subjects)

Discovery to Recovery: Translation is one Key

Bench ⟺ Bedside ⟺ Practice

Pathophysiology
Genetics
New treatments

Clinical Trials Networks
Practical trials
Services research

Discovery to Recovery: Partnership is the Other

Families

Clinicians

Scientists

Autism and the Federal Govt.

- Coordinated effort via DHHS, with public partners
- Repositories – infrastructure developed
- Strategic plan in place – Early intervention is a priority!

However:

- Workforce is narrow – services are sparse
- Field still lacks targets
- Phenotype needs better definition

RESEARCH = HOPE

www.nimh.nih.gov