

Autism Research at National Institute of Mental Health

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National Institute of Mental Health

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Interagency Autism Coordinating Committee (IACC)

Combating Autism Act of 2006 (P.L. 109-416)

- Department of Health and Human Services
 - Administration on Families and Children
 - Centers for Medicare and Medicaid Services
 - Centers for Disease Control and Prevention
 - Health Resources & Services Administration
 - National Institutes of Health
 - Office on Disability
 - Substance Abuse & MH Services Administration
- Department of Education

IACC Services Subcommittee

Vision:

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

Mission

- To assess and improve services and supports for people with ASD

IACC Strategic Plan for Autism Spectrum Disorder Research

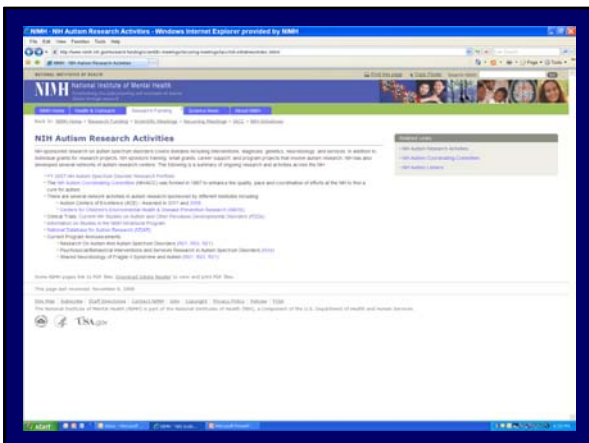
As a federal advisory committee established by the Combating Autism Act of 2006, the IACC is mandated to develop and annually update a strategic plan for the conduct of, and support for, autism spectrum disorders research.

FY 2007 NIH Autism Portfolio

Total Autism Funding by Research Area

- Biology – 29%
- Treatment – 14%
- Diagnosis – 16%
- Risk Factors – 22%
- Other – 18%

<http://www.nimh.nih.gov/research-funding/scientific-meetings/recurring-meetings/iacc/nih-initiatives/fy-2007-nih-autism-spectrum-disorder-research-portfolio.shtml>



NIH Autism Centers of Excellence

ACE grants support a broad range of autism research

- rare genetic variants and mutations
- associations between autism-related genes and physical traits
- early brain development and functioning
- possible environmental risk factors and biomarker
- social interactions in infants
- potential new medication treatment

The program includes research centers and research networks.

- The centers foster collaborations between teams of specialists at the same facility to address a problem in depth.
- The networks consist of researchers at facilities throughout the country working together on a single research question.

<http://www.nimh.nih.gov/science-news/2009/newly-awarded-autism-centers-of-excellence-to-further-autism-research.shtml>

National Database for Autism Research

A collaborative bioinformatics system created by NIH to support research in autism spectrum disorder (ASD) and accelerate scientific discovery. NDAR goals:

- Develop standards to promote meta-analysis and cross site data comparisons.
- Provide researchers access to useful software tools and infrastructure.
- Promote sharing of research data relevant to ASD.

<http://ndar.nih.gov/ndarpublicweb/>

NIMH Intramural Research Program

Pediatrics & Developmental Neuropsychiatry Branch

Autism Spectrum Disorders

- Clinical and Immunological Investigations of Subtypes of Autism
- An investigation of the Relationship between Donepezil Enhanced REM Sleep, Sleep Architecture and Behavior in the Prepubertal Child with Autism
- Treatment of Childhood Regressive Autism with Minocycline

Rett Syndrome

- Clinical and Immunological Investigations of Subtypes of Autism

Healthy Children

- Clinical and Immunological Investigations of Subtypes of Autism

<http://intramural.nimh.nih.gov/pdri/>

The screenshot shows a web browser window displaying the NIMH website. The page is titled "Division of Intramural Research Programs (DIRP)" and lists several research programs. The first program is "Clinical and Immunological Investigations of Subtypes of Autism", which is described as a study of children with autism spectrum disorders (ASD) and typically developing children (TD). The second program is "Risperidone medication treatment of the repetitive behaviors and compulsions of Autism Spectrum Disorders", which is described as a study of children and adolescents with ASD who have not had adequate response to treatment or who could not tolerate the treatment. The page also includes navigation links for "Home", "About", "Research", "Treatment and Services", and "Contact Us".

Division of Neuroscience and Basic Behavioral Science - NIMH

Supports research programs in:

- Basic neuroscience
- Genetics
- Basic behavioral science
- Technology development
- Drug discovery
- Research dissemination

Contributes to the generation and dissemination of relevant basic science knowledge to create improved diagnosis, treatment, and prevention of mental and behavioral disorders

Division of Developmental Translational Research - NIMH

Supports translational research to discover the developmental origins of mental disorders, their prevention & cure, including:

- Understanding the influences of genetics, brain development, environment, and experience that lead to psychopathology
- Develop, test, and validate bio-markers (e.g., genetic, imaging) to improve diagnosis, identify risk, and personalize treatment
- Identify early signs of risk and develop novel and personalized preventive and treatment interventions
- Assess the mechanisms of action of efficacious interventions

Division of Services and Intervention Research - NIMH

Research to evaluate the effectiveness of interventions, including:

- pharmacologic, psychosocial, somatic, rehabilitative and combination interventions on disorders-including effects on functioning

Mental health services research including:

- Services organization, delivery, and health economics at the individual, clinical, program, community and systems levels in various settings

- Interventions to improve the quality and outcomes of care

Clinical epidemiology of mental disorders across clinical and service settings.

Dissemination/implementation of evidence-based interventions into service settings.

Research Areas

- Intervention development, testing and adaptation
- Dissemination and implementation
- Early screening
- Successful referral
- Evaluation and diagnosis
- Connection to treatment(s)
- Supports for treatment and services
- Coordination of services
- Supports for community retention

ASD Treatment Options

Applied Behavioral Analysis

- Ivar Lovaas and colleagues, UCLA
- Reducing inappropriate behavior and increasing communication, learning and appropriate social behavior
- Intensive one-on-one child-teacher interaction for 40 hours per week

Other Behavioral Management

- Reinforce desirable behaviors, reduce undesirable ones
- Build on child's interests
- Predictable schedule
- Teach tasks as a series of simple steps
- Actively engage child's attention in structured activities
- Regular reinforcement
- Change as appropriate for age and dev't

Dietary Interventions

Concept: food allergies or vitamin/mineral insufficiency cause autism

- Gluten-free diet (wheat, oat, rye, barley)
- Casien-free diet (principal protein in milk)
- Dietary supplements (B6 and magnesium)
- Secretin (diagnose GI problems)

★ No consistent empirical findings on the effectiveness of any of the above

Medications

Used for behavioral problems: aggression, self-injury, severe tantrums

- Risperidone/Risperdal – for aggression
- Off-label antipsychotics – aggression and self harm
- Antidepressants – SSRIs
- Anticonvulsants
- Ritalin

Services

- Family support and education
- Coordination and support of treatment
- System navigators
- Transition to adulthood
- Community-living supports
- Supported employment

Autism Spectrum Disorders Services in the United States

Ellen W. Blackwell, MSW
Centers for Medicare & Medicaid Services
November 21, 2008



Major Funding Streams for Autism Spectrum Disorder (ASD) Services

- Family
- Private
- Government (Federal, State, local)
 - Education
 - Social Security
 - Medicaid
 - Medicare
 - Child Welfare
 - Justice (Corrections)



Where Are Children with ASD Educated?

- Special classrooms in regular or home schools
- General education classrooms for all or part of the school day
- Center-based programs
- Private schools
- Home



Private Health Insurance for Children with ASD

- Coverage often limited to medical services
- Some insurance companies may deny coverage based on an ASD diagnosis
- Most coverage debates are aimed at "Applied Behavioral Analysis" (ABA) treatment, and speech and occupational therapies
- ABA is a treatment philosophy that includes certain services and supports designed for a particular child
- Some States require private insurers to cover ABA treatment: AZ, TX, LA, MN, FL, SC, IN, PA*
- ABA treatment covered by insurers typically has maximum yearly or lifetime benefits

*Source: Autism Speaks



Supplemental Security Income

- Social Security disability benefits are different from Supplemental Security Income (SSI) benefits
- Most people with ASD receive SSI benefits
- SSI benefits are paid monthly to low-income disabled children and adults
- Disability definition/qualification is very complex



Medicaid

- Title XIX of the Social Security Act (Act)
- Established in 1965 as a companion to Medicare
- Medicaid provides health and Long Term Care (LTC) services
- Joint Federal/State entitlement program
- States determine their own unique programs
- Some services are mandatory, others optional



Medicaid Benefits

MANDATORY

- Physician services
- Laboratory & x-ray
- Inpatient hospital
- Outpatient hospital
- EPSDT
- Family planning
- Rural and federally-qualified health centers
- Nurse-midwife services
- NF services for adults
- Home health

OPTIONAL

- Dental services
- Therapies – PT/OT/Speech/Audiology
- Prosthetic devices, glasses
- Case management
- Clinic services
- Personal care, self-directed personal care
- Hospice
- ICFs/MR
- PRTF (psychiatric) for children <21
- Rehabilitative services
- Home & Community Based Services for the Elderly and Disabled



Dual Eligibility

- Some people with ASD could be dually eligible for Medicare/Medicaid
- Medicare pays for physician/hospital care, Medicaid pays for LTC
- About 8 million people - most costly and frail in both programs
- About half live in Nursing Facilities
- Most have annual incomes <\$10,000/year
- Represent about 40% Medicaid costs, 25% Medicare costs



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What Statutory Services May Be Included in a HCBS Waiver?

- Case Management
- Homemaker Home Health Aide
- Personal Care
- Adult Day Health
- Habilitation
- Respite Care
- Services for individuals with chronic mental illness: Day Treatment, Partial Hospitalization, Psychosocial Rehabilitation, Clinic Services
- “Other” services to avoid institutionalization



Waiver Authorities in Medicaid

- Section 1915(b) – managed care services, selective contracting
- Section 1915 (c) – home and community-based services (HCBS)
- Section 1115 demonstrations (AZ, VT, HI)



What Other Services Might Help a Person with ASD?

Some examples:

- Assistive technology
- Behavior management
- Day Program
- Supportive employment
- Dental
- Family/caregiver training
- Independent living skills training
- Nutritional counseling
- Community transition



How Can Self-Direction Benefit People with ASD?

- People with ASD and their families may exercise decision-making authority over HCBS
- Recruiting, hiring, and firing staff are permitted
- Budget authority allows people to pay for their own services
- Self-direction may work better for people not served well by the traditional agency-based model
- Self-direction can save money & increase satisfaction with services
- Room and board costs (rent, food, utilities) are challenging for individuals with only SSI income



ASD-Specific HCBS Waivers

- Indiana – approved 1990 – serves about 600 people
- Maryland – approved 2000 – serves about 900 children
- Wisconsin – approved 2003, serves about 3,000 people
- Colorado – approved 2005, serves about 160 children
- South Carolina – approved 2006, serves about 600 children
- Maine – approved 2007 – serves about 2,000 people
- Massachusetts – approved 2007, serves about 80 children
- Kansas – approved 2008, serves about 50 children
- Pennsylvania – approved 2008, serves about 200 adults

*Pennsylvania – 1915(a) contract, Nebraska concurrent 1915(b)(c), Montana Section 1915(c), Washington Section 1915(c), Iowa SPA, – under review



What Does the Future Hold?

- Most people with ASD need services & supports throughout their lives
- About half the States are facing significant budget shortfalls and slower than anticipated revenue growth
- Rising unemployment increases Medicaid rolls
- States are continuing to use HCBS and managed care options to achieve integrated LTC savings
- An uncertain economy will have implications for ASD services, and services to all citizens with disabilities



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