

The background of the slide features a large, faint, red circular seal of Rutgers University. The seal contains the text 'RUTGERS UNIVERSITY' and 'THE STATE UNIVERSITY OF NEW JERSEY' around its perimeter. In the center of the seal is a sunburst design. The word 'RUTGERS' is prominently displayed in a large, white, serif font at the top left of the slide.

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THE STATE UNIVERSITY
OF NEW JERSEY

Autism Research: Strengths and Needs in New Jersey

**Governor's Council for Medical Research and Treatment of Autism
Scientific Meeting of the Basic and Clinical Research Grantees**

March 23, 2012

Center for State Health Policy
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Overview

Briefly review national funding priorities – IACC and Autism Speaks

Overview autism-related funded research in New Jersey
Catalog of grants funded from 2005 to 2010

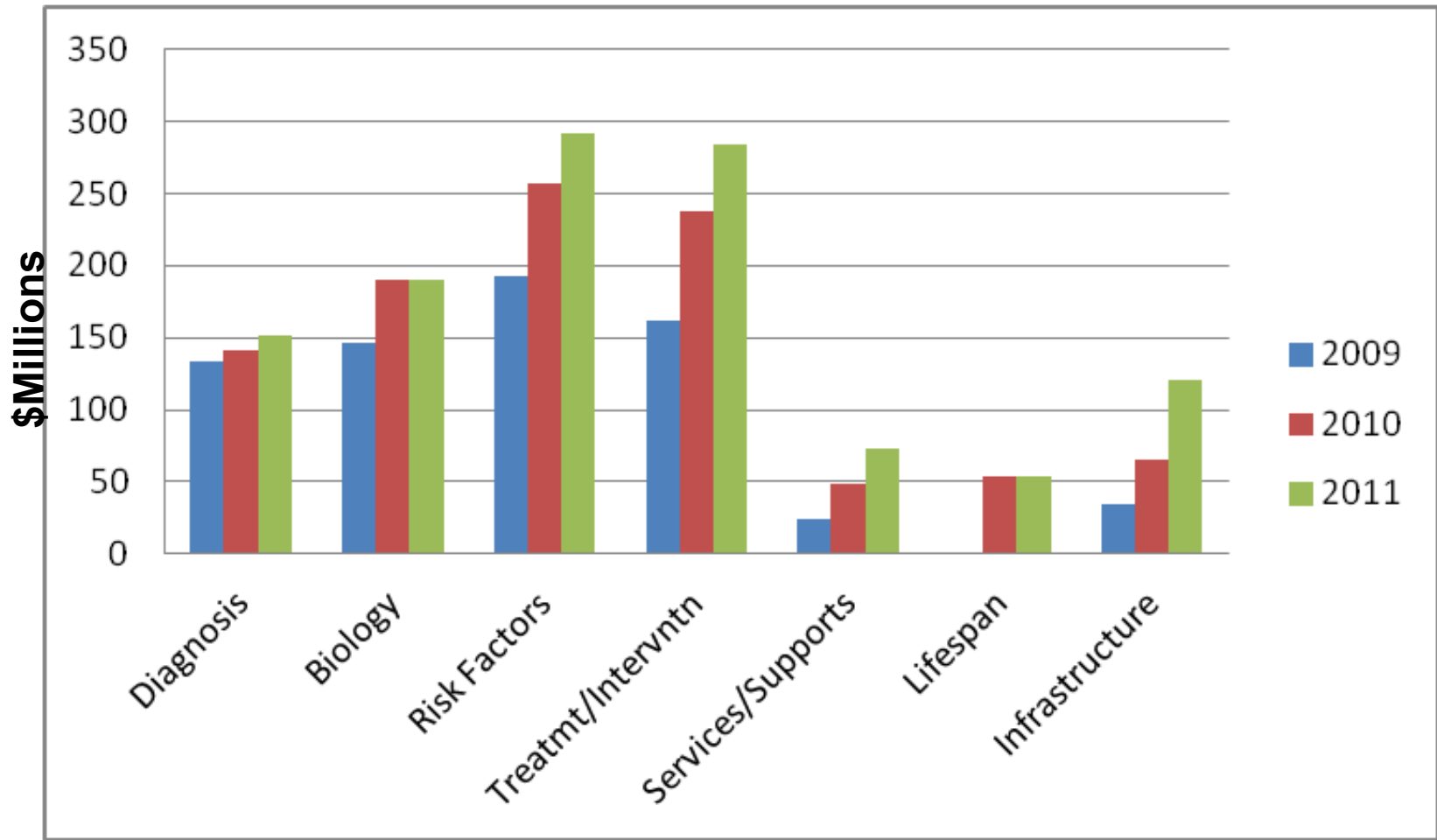
Share information from follow-up interviews with researchers and other experts

Suggest some areas of potential opportunity for increasing autism-related research in New Jersey

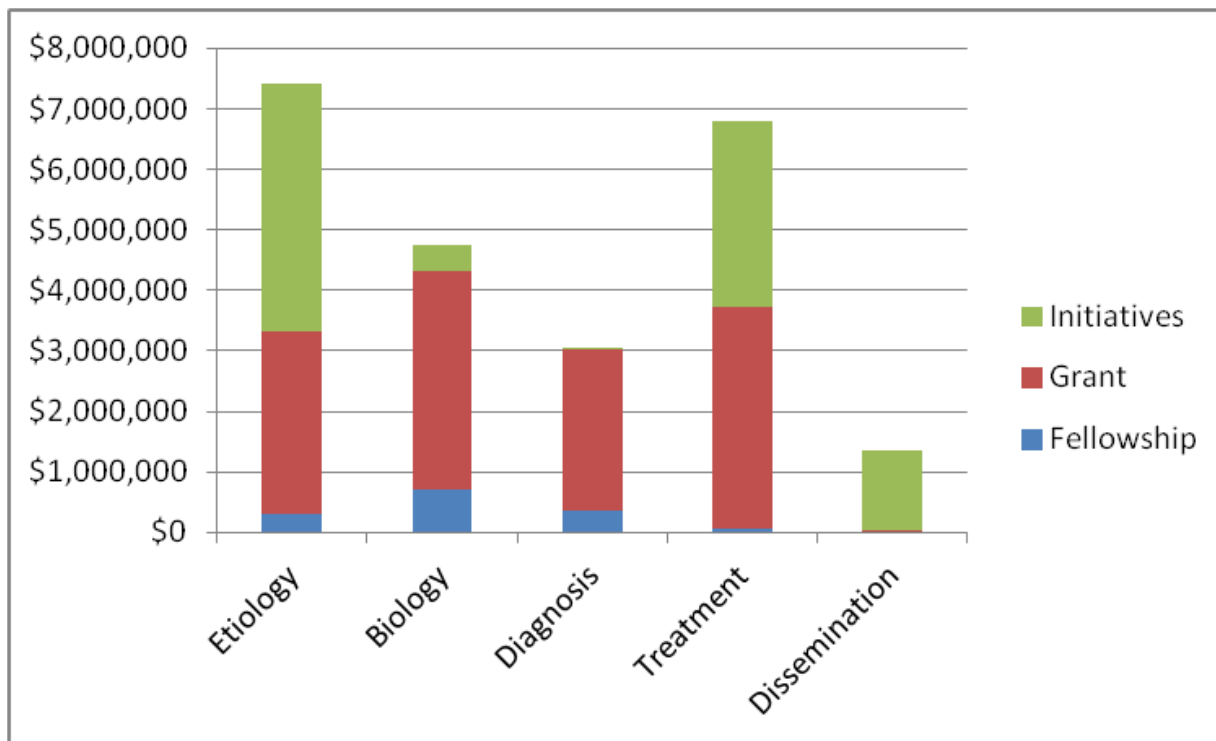
Interagency Autism Coordinating Committee (IACC)

- Provides direction for ASD-related research activities of US Department of Health and Human Services
- Topic areas:
 - Diagnosis/Identification—When should I be concerned?
 - Biology—How can I understand what is happening?
 - Risk Factors—What caused this to happen and can it be prevented?
 - Treatment/Intervention--Which treatments and interventions will help?
 - Services/Supports—Where can I turn for services?
 - Lifespan—What does the future hold, particularly for adults?
 - Infrastructure/Surveillance—What other infrastructure and surveillance needs must be met?

IACC Funding Recommendations, 2009-2011



Autism Speaks Science Funding by Type and Portfolio, 2009



Autism Speaks focuses on riskier, more innovative programs and dissemination of research findings to families and general public

Needs Assessment for Strategic Planning

Method:

- Web and database search of autism-related studies awarded to NJ researchers from 2005-2010
- 40 key informant interviews with 48 people
 - Snowball sampling: recommendations from Council and other experts
 - 13 researchers
 - 5 directors or researchers from autism centers of excellence
 - Others included Council members, families, clinicians specializing in ASD, healthcare and service providers, state agency staff
- Semi-structured interviews, open-ended questions about ASD biomedical research, diagnosis and treatment, training and education
- Project team reviewed interview notes to identify themes

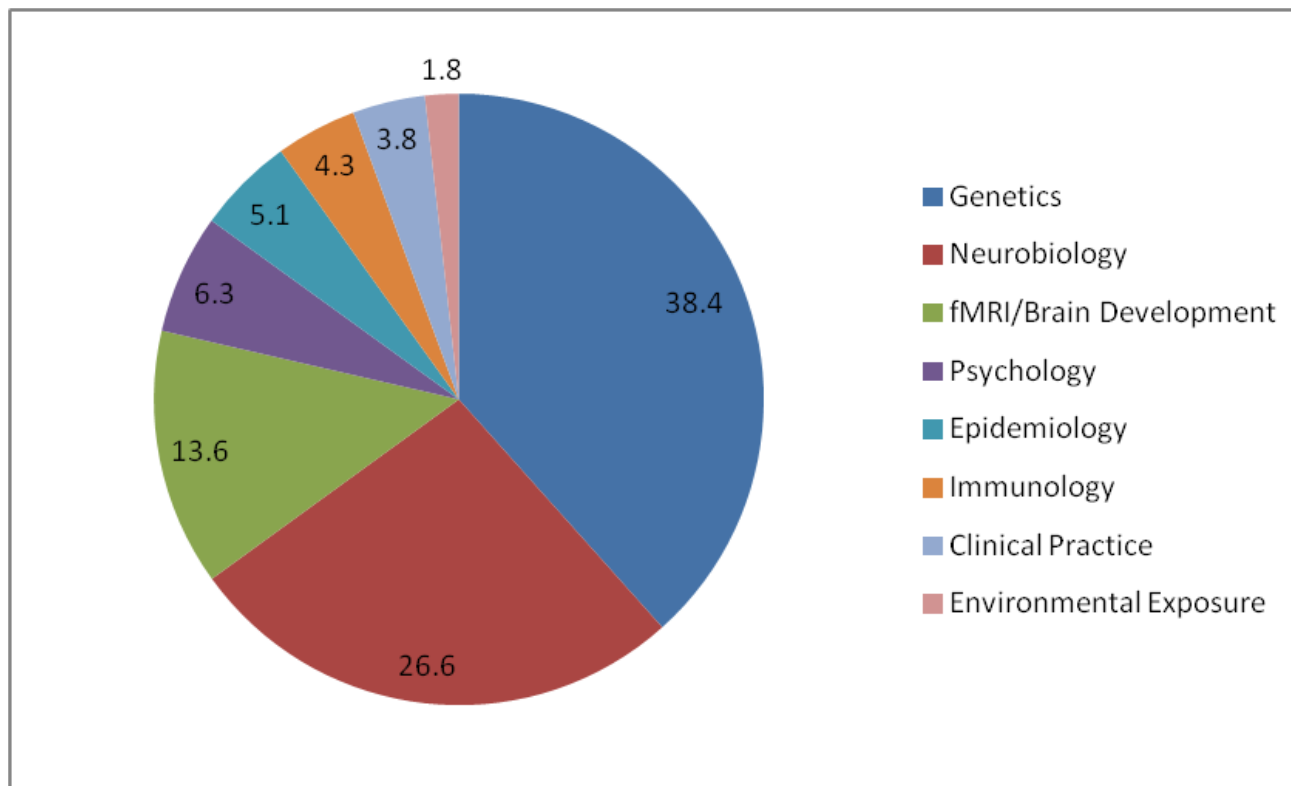
Autism-related Grants to NJ Researchers, 2005-2010

- Over 80 research grants awarded to NJ researchers, many with multiple years of funding
- Total ASD-related research funding over \$103 million, including \$70 million for tissue repository
- Funders included
 - National Institutes of Health (NIMH, NICHD, NINDS, NIEHS, NIA, etc.)
 - Autism Speaks
 - Simons Foundation
 - National Center for Birth Defects and Developmental Disabilities
 - Autism Research Institute
 - ASPEN
 - Governor's Council
 - Pharmaceuticals (we could not identify all of these)

Academic Institutions Funded

- NJ Institute of Technology - immunology
- Princeton University - genetics, brain function, neurobiology
- Rutgers University – genetics, neurobiology, brain function, psychology
 - Human Genetics Institute of New Jersey (\$70 million)
- University of Medicine & Dentistry of New Jersey – genetics, neurobiology, immunology, epidemiology, environmental exposure, treatment
 - New Jersey Medical School
 - Robert Wood Johnson Medical School
 - School of Osteopathic Medicine
- NIA, NIMH, and Autism Speaks funded research training and mentored research for pre- and post-doctoral students

Funding for NJ Individual Researchers, 2005-2010



Does not include tissue repositories, training, or pharmaceutical trials.

Strengths of Autism Research in New Jersey

- Many researchers have ongoing national funding
- Several researchers have used Council funding to explore new areas and advance research agenda—springboard to new funding
- Researchers at different institutions have collaborated, particularly in basic science studies
- Academic researchers have had some successful collaborations with clinical practitioners and would welcome more
 - Need to find ways to support clinician time for research
- Several clinical centers have participated in pharmaceutical studies and collaborations with autism centers outside NJ

Opportunities for NJ Research

- ASD in underrepresented and underserved populations
 - New Jersey has a diverse population within a manageable geography – racial/ethnic, cultural, economic, urban/rural, literacy level
- ASD surveillance and epidemiology
 - Big gap in information about adults-national as well as local need
 - Studies to carefully describe diverse individuals with ASD can lead to more diversity in treatment studies
- Environmental risk factors
 - Autism Speaks and IACC priority to develop analytic tools for examining gene-immune system-environment interactions
 - Enhance collaboration between clinicians and scientists to study autism susceptibility

Research Topics Suggested by Key Informants

- Test and disseminate standardized tools for evaluating very young children
- Develop cohort of siblings of children with autism
- Characterize cohort of teens with ASD to study developmental plasticity and opportunities for intervention
- Design and pilot interventions focused on meaningful outcomes for individuals with ASD transitioning to adulthood
- Applied research on treatment approaches to co-morbid conditions (GI, sleep, mental health)
- Examine metabolic-immune system interactions
- Increase number of researchers/studies using brain imaging in connection with other methods, e.g., linking brain function and behaviors

Ideas from other Autism Centers

- Effective collaboration is key to success of a center of excellence
 - Collaboration between medical professionals and researchers critical for major studies
 - Many leading studies are multidisciplinary, multi-site
 - Leadership must model collaboration
- Comprehensive, multidisciplinary care is important
 - Build relationships with participating families
 - Can provide resources for standardized diagnostic, biological, medical and treatment data
 - Portfolio of clinical research is necessary component of a center
- Participating institutions must make a commitment to autism as an area of focus