



**Needs Assessment to Inform the Development of a
Strategic Plan for the Governor's Council for Medical
Research and Treatment of Autism**

Phase 2 Report

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Needs Assessment

Phase 1

Gather and review background information

- Previous New Jersey reports

- National priorities for autism-related biomedical research

Catalog autism-related funded research in New Jersey

Phase 2

Key informant interviews with stakeholders in New Jersey and national experts

Phase 1 Findings

- Over 80 research grants awarded to NJ researchers
- Total ASD-related research funding over \$103 million
- Diverse funding from NIH, Autism Speaks, SFARI, EPA
- Active research at UMDNJ, Rutgers, Princeton, NJIT
- Bulk of studies in genetics, neurobiology, fMRI/brain development

Phase 2

- 40 key respondent interviews
 - Snowball sampling: recommendations from Council and other experts
 - Feedback from 48 people
 - 8 Council members
 - 10 family members
 - 13 researchers
 - 14 healthcare providers
 - 13 service providers
 - 5 staff of NJ state agencies
 - 5 directors or researchers from autism centers in other states
 - Semi-structured interviews; open-ended questions
 - Project team reviewed interview notes to identify themes

Research Strengths in New Jersey

- General agreement from researchers that NJ research should mesh with national agenda
- Several researchers have used Council funding to explore new areas and advance research agenda—springboard to national funding sources
- Many researchers with ongoing federal funding for ASD research
- Researchers aware of national funding opportunities
- Examples of successful collaboration between autism researchers
 - Between researchers at different institutions
 - Between basic researchers and experienced clinicians
 - With autism researchers in other states

Opportunities for Future Research

- More focused and coordinated approach for NJ research agenda
- Advantage of diverse population and manageable geography
- Test and disseminate standardized tools for evaluating very young children
- Applied research on treatment approaches with well-characterized samples , e.g., co-morbid conditions
- Design and pilot interventions focused on meaningful outcomes for individuals with ASD transitioning to adulthood—national relevance
- Epidemiological studies of diverse population with ASD in NJ--could lead to more diversity in treatment studies
- Partner with pharmaceutical companies to study drugs and other substances (e.g., oxytocin, glutamine) with well-characterized samples

Diagnostic Evaluations and Medical Treatments

- Many excellent organizations in NJ: e.g., Children's Specialized, Hunterdon, CNNH, Eden, PCDI, Bancroft Neurohealth, NSTM
 - Too few opportunities to exchange information and compare approaches
- Need to improve early screening and identification:
 - not all pediatricians are knowledgeable
 - too few children in Autism Registry before 3
 - minority children and those in families with multiple problems likely to be missed
- Shortage of specialists (e.g., pediatric neurologists, developmental pediatricians, psychiatrists)
- Too few providers experienced with ASD (e.g., physicians, psychologists, early intervention, special education teachers)
 - No good picture of workforce capacity

Diagnostic Evaluations and Medical Treatments

- Gaps in diagnosis and treatment for those with most complex problems, e.g., co-morbidities, mental health/behavioral issues
- Gaps in treatments for older teens and adults with ASD—many seeing child providers
- Autism centers of excellence provide multidisciplinary diagnosis and treatment in one location; many adopt medical home models
 - Supportive services and welcoming environment for families
 - Requires collaborative model
 - Requires institutional commitment
- Role of NJ ACE could be to promote best practices and consistency throughout NJ
 - Should other state-specific issues be part of NJ ACE mission?

Training Programs on Biomedical Treatment, Diagnosis, and Prevention

- Education for pediatricians: Autism NJ, NJ PCORE (NJ EPIC), clinical enhancement centers, others – progress, but more is needed
- Training for nurses in screening and assessment -- model is increasingly popular – training in schools of nursing?
- Training for autism professionals in evidence-based practice: Autism NJ, more is needed
- More ABA-trained professionals
- Additional training for first responders – urban areas, follow-up training on effective techniques for dealing with individuals with ASD
- Information about complementary and alternative treatments
- Respondents believe Council could make a contribution
 - Consult on best approaches to evidence-based professional training
 - Publicize advances in diagnosis and treatment in a timely manner

Information and Education for Families and Public

- Clinicians say families need help in evaluating info about treatments—what to expect, how to evaluate effectiveness
- Autism NJ, POAC, hospitals provide education and support for families – some families have access problems
- Needs include:
 - Where to go for services
 - How to deal with medical issues
 - How to deal with behavior problems
 - What does science say about effectiveness of treatments?
- Autism centers of excellence provide support and information for families, disseminating findings to public growing part of funding requirements
- Respondents feel Council can provide contribution

Perceptions of Council's Role

- Researchers aware of Council funding and see value
- Clinical enhancement centers feel funding allowed them to improve screening – would like Council to promote more exchange of ideas about diagnosis and treatment
- Confusion about Council's mission – Improve services? Research? Public education?
 - Council needs to do better job of publicizing mission and successes
 - Council activities not transparent to public
- Concerns about functioning of Council, e.g., clarity of goals, accountability for results of grant funding, lack of tracking of outcomes, ethical conflicts
- Constant administrative changes have been challenge
- Many respondents feel hopeful that things are improving

Key Ideas from other Autism Centers

- Effective collaboration is key to success of autism center of excellence
 - Leadership must model
 - Collaboration between medical professionals and researchers critical for major studies
 - Many studies are multidisciplinary, multi-site
- Research studies should focus on meaningful outcomes and careful characterization of individuals
- Comprehensive, multidisciplinary care important for good research
- Home institution must make commitment to autism as area of focus

Questions?

Discussion?