

Child Health Working Group Report: Analysis of Existing Strengths, Critical Gaps, and Opportunities for Collaboration
May 2014

Analysis

Identify existing strengths, including a table that prioritizes sub-areas of funding and publications (2 pages)

Regarding the concepts of “pediatrics,” “child health,” “adolescent/young adult health,” and “child development,” an analysis was conducted of research funding (federal/state government and private), service funding (federal/state and private), and peer-reviewed journal publications, as well as local, state, and national needs. The analysis focused primarily on “recent,” defined as being within the past 5 years, Rutgers University (RU) awarded funding and RU author publications.

Because of recent increased research funding opportunities, limited evidenced-based models of cause and best clinical practices, a growing global need, and recognition of higher than average rates of autism in New Jersey (NJ), the Child/Adolescent Health work group strongly recommends the development of an Autism Spectrum Disorder (ASD) institute (Table 1). Currently, multiple strengths are already in place at RU (see Table 2); therefore, this proposal has the potential to be an example of a “Best in Class” initiative of collaborative efforts among RU schools, departments, and community, state, national, and international participants.

The following have been identified as RU strengths for the development of a world-renown institute of research, education, public policy development, and clinical care related to ASD. In addition to the award of millions of dollars in past and current federal (NIH and CDC) research funding related to ASD, and peer-reviewed journal article publications, RU offers a multitude of opportunities across the state of NJ for collaborations among faculty and staff in its 33 schools and colleges. Of great significance, for any biomedical or health science initiative, is engagement with the community. Currently, several community-based collaborations between RU and community based programs, including Autism NJ, 4H, public school systems, and private school systems in NJ, exist and serve as another strong asset to RU. RU as a statewide system provides the opportunity for a networked system of programs, including expanding geographic access to services for children and young adults with ASD and their families.

TABLE 1
RECENT RUTGERS ASD RESEARCH AWARDS, PUBLICATIONS, AND FEDERAL RECOGNITIONS

	Research Grants (within the past 5 years)	Recent Publications (within the past 5 years)	Service Grants (within the past 5 years)	Rutgers ASD Programs, Initiatives, and Collaborations	Recognized Center of Excellence
Autism Spectrum Disorder	29	49	9	18	1

TABLE 2* - CURRENT ASD-RELATED PROGRAMS AT OR AFFILIATED WITH RUTGERS

Program	Location	RU School	Current/Past Research Funding	Non-Research Funding	Clinical ASD Services	Education Services	Public Service
Douglas Developmental Disabilities Center	New Brunswick	Applied and Professional Psychology	NJCA**; Organization for Autism; several training related endowments/gifts	Yes	Yes	Yes	Yes
NJ Autism Study	Newark	NJMS	CDC	No	Yes	Yes	Yes
Autism Clinic-RWJUMG	Piscataway	RWJMS-Psychiatry	NARSAD; NIH-NCCAM division; NJCA**	Yes	Yes	Yes	No
NJ Language and Autism Genetics Study	New Brunswick	Arts and Sciences - Genetics	NIMH; NJGCMRTA***	No	No	Yes	No
Sensory Motor Integration Lab	New Brunswick	Arts and Sciences - Psychology	National Science Foundation; NJGCMRTA	No	No	Yes	Yes
Children's Specialized Hospital	New Brunswick	RWJMS Collaboration	NJGCMRTA; Health Care FDN of NJ	Yes	Yes	Yes	No
The Boggs Center on Developmental Disabilities	New Brunswick	RWJMS - Pediatrics	NJGCMRTA; CDC	HHS, NJ State Agencies; FDNs	No	Yes	Yes
The Brain Health Institute	Piscataway	RWJMS - Neuroscience	NIH; Dana FDN; NJGCMRTA	No	No	Yes	No
Institute for the Study of Child Development	New Brunswick	RWJMS	NJGCMRTA; NIH	No	No	Yes	No
Child Evaluation Center/Autism Center	Newark	NJMS	NJGCMRTA (Autism Center)	NJ DOH (CEC)	Yes	Yes	Yes
The Institute for Genomic Medicine	Newark	NJMS	Yes	No	Yes	Yes	Yes
Department of Child/Adolescent Psychiatry	Newark	NJMS	Yes	No	Yes	Yes	Yes
Mom2Mom	Piscataway	UBHC	No	NJ Dept. of Children & Families	No	Yes	Yes
RU Cell and DNA Repository	Piscataway	RWJMS	NIH; Department of Defense	No	No	Yes	No
Rutgers Brain Imaging Center	Newark	NJMS	Yes	No	Yes	Yes	No
Child Health Institute of NJ	New Brunswick	RWJMS	NIH	No	No	Yes	No
Center for Advanced Infrastructure and Transportation	Piscataway		No	NJCA**	No	Yes	Yes
College Support Program for Rutgers Students with ASD (CSP)	New Brunswick	Health Services	No	No	Yes	Yes	No

*Data still being collected on current funding sources **New Jersey Governor's Council on Autism

***New Jersey Governor's Council on Medical Research and Treatment of Autism

Identify critical gaps

Due to increasing rates of ASD diagnosis globally and specifically in NJ there is an urgent need for multidisciplinary research, diagnostic evaluations, clinical care, education, family support, transition guidelines and models of care for persons with ASD. Components of each of the identified needs are occurring at RU, and RU affiliated sites across NJ, as well as other institutions nationally, but there is no central coordination and repository of best practice and research models as it relates to ASD. As with other chronic conditions, early diagnosis, early linkage to ASD-expert providers and engagement in ongoing interventions relates to better long-term outcomes and quality of life of persons with ASD.

RU currently lacks a strong, nationally recognized clinical research leader to head the proposed institute. Having a strong clinical research Director is necessary to allow Rutgers to apply for ACE type NIH funding since this is a pre-requisite for this type of funding. Currently, financial support is primarily dependent on grant funding, and many programs are dependent on grant-to-grant funding to remain operational. This directly affects ongoing study of biomedical, environmental and social conditions that have an impact on ASD, as well as development, implementation and evaluation of clinical care programs, and the implementation and maintenance of a population-based database surveillance system. Until approximately two years ago, a multi-specialty ASD care program was developed and operated by NJMS faculty, however; it was disbanded as a result of grant funding elimination. Unfortunately, since that time, the rate of ASD in NJ has increased. While some evidence-based educational interventions have been identified, translation of these interventions into practice has not been done across all educational settings. A shortage of developmental and behavioral clinical resources has resulted in large and long waiting lists for diagnosis and treatment of ASD. Primary care providers, with limited training in ASD and related disorders, are often the only point of contact for care and provide guidance to families without access to expert consultation. Additionally, curricula to educate our next generation of health professionals, educators, policy makers, and other scientists as to the complexities of ASD are limited.

RU has become one of the largest health science academic centers at a public university in the United States (US), and has the opportunity to coordinate efforts for a better understanding of ASD (through research), develop and implement clinical care models of excellence (NJ has the highest rate of ASD among the 11 states doing surveillance), design educational curriculums and interventions, and provide expertise to best serve the ASD community. For example, centralizing the administrative needs of processing all ASD grant applications would reduce administrative barriers for grant submissions and reports (for both research and practice grant submissions). Creating individualized support systems for new researchers, setting up a network of mentors to provide support to researchers and implementing a synergistic and collaborative approach across all aspects of research is urgently needed.

Another identified gap that would be filled by establishing a network of ASD multidisciplinary researchers, clinicians, educators, and policy/legal experts, is that of resource sharing and communication among ASD experts in NJ. Such a network of ASD experts, would allow supportive collaborations with other departments or schools within RU that are interested in ASD work. Examples include the School of Pharmacy, interested in doing neuropharmacological research and clinical trials for ASD symptom management, the Center for Molecular and Behavioral Neuroscience which is internationally recognized for using a multidisciplinary approach for the analysis of biological determinants of behavior and the Department of Cell Biology and Neuroscience which can maximize research efforts with animal models because of the existence of animal research facilities. Nationally, there is no single academic center of excellence that is addressing ASD in a comprehensive manner. There are 3 NIH research funded (P50) Autism Centers of Excellence (ACE), and 8 research network sites (RO1 and U01 funded). But these are not comprehensive clinical and educational programs.

Identify opportunities for collaboration

The Child/Adolescent Health work group proposes each of the following RU Schools having faculty affiliated with the Rutgers ASD Institute:

- Center for Advanced Infrastructure and Transportation
- Center for Collaborative Genomic Studies on Mental Disorders
- Graduate School of Applied and Professional Psychology
- Graduate School of Biomedical Sciences
- Graduate School of Education
- Institute for Human Genetics
- Institute for Health, Health Care Policy and Aging Research
- Medical Schools: NJMS and RWJMS (in particular, Pediatric Divisions of Neurology/ Developmental Disabilities, Genetics, Neuroscience, Cell Biology, Child/Adolescent Psychiatry, Preventive Medicine & Community Health, Pharmacology & Physiology)
- School of Arts & Science (Psychology, Neuroscience, Computer Science)
- School of Dental Medicine
- School of Engineering
- School of Law
- School of Nursing
- School of Pharmacy
- School of Planning and Public Policy
- School of Public Health (Departments of Epidemiology, Health Education & Behavioral Science, Health Systems & Policy)
- School of Social Work

Continued collaborations and partnerships between Rutgers ASD Institute and the following community health-related affiliated programs include:

- Pediatric Academic Health Campus in New Brunswick – Department of Pediatrics at RWJMS, Child Health Institute of New Jersey, Children’s Specialized Hospital, and Bristol-Myers Squibb Children’s Hospital at Robert Wood Johnson University Hospital
- New Jersey Institute of Technology (NJIT) - biomedical engineering and computer based technology
- Jersey Shore Medical Center – affiliate teaching hospital of RWJMS students; faculty appointment, and pharmaceutical research
- State of NJ Department of Health (DOH) – ASD registry
- NJ Department of Human Services - Division of Developmental Disabilities and Office of Autism
- NJ Governor’s Council for Medical Research and Treatment of Autism – research; clinical care

Existing collaborations with potential for continued partnerships with the Rutgers ASD Institute:

- Autism NJ – collaborates with Mom2Mom program at NJMS
- NJ Department of Education
- NJ Department of Children and Families
- Montclair State University - state funded for coordination of ASD research-funded activities in NJ (Montclair Center)

Possible funding or partnering sources for Rutgers ASD Institute:

- National Institute of Health (NIH) – research funding

- NJ Governor’s Council for Medical Research and Treatment of Autism – research; clinical care
- Department of Health & Human Services, Human Resources and Services Administration (HRSA) – clinical care funding
- Centers for Disease Control and Prevention (CDC) – surveillance; epidemiological work
- Robert Wood Johnson Foundation – clinical care; research
- Private donations and private foundations (>350 biotech companies in NJ)
- Autism Speaks – research
- Doug Flutie Jr. Foundation – education and advocacy
- Simons Foundation Autism Research Initiative – research
- HRSA Block grant (Title V) funding – maternal/child health care systems
- NJ DOH

Summary paragraph on the relative opportunity to be “best in class” compared to other institutions

The rate of new diagnosis of ASD has been increasing in the US, and the median age of first diagnosis is beyond the first four years of life; making ASD a serious national health concern. Currently the median age of first ASD diagnosis in the U.S. is 53 months (4 years 5 months), even though diagnosis can be made as early as 24 months of age. This is too late to initiate early interventions. While the rate (1 in 68 children age 8 years in the US¹) is increasing (from 1 in 152 children age 8 years in the U.S. in 2002²), the median age of diagnosis has not significantly changed.^{1,2} NJ has been identified as having the highest rate of ASD in children and adolescents in the US of the 11 states being monitored, and has become known as a state with known ASD specialists and research. Many of these specialists are at or affiliated with RU, which is ranked 24th nationally in research and development of all universities, and 16th of all public universities.³ Despite the tremendous efforts made to date to understand the causes and correlates of ASD, much is still unknown. Because autism is a spectrum disorder, not every child, adolescent or young adult with ASD has the same level of impact or disability and the diagnosis is based solely on psychiatric diagnostic criteria. This makes the diagnosis much more challenging, and often results in delayed diagnoses. Yet, early diagnosis allows for earlier interventions to assist in providing optimal care and hopefully increasing the quality of life for persons with ASD and their families. Combining expertise from its schools, it is proposed that RU become an interdisciplinary and holistic state-of-the-science institute of excellence in ASD. RU is well known for its partnership with community, foundations and governmental agencies and having a dedicated comprehensive ASD institute will enhance the university’s reputation both nationally and internationally. Through the multidisciplinary networking, research findings, and translation of clinical and educational interventions, the goal within 5 years is to see a significant decrease in age of first diagnosis, age of engagement in ASD care and services, and increases in all areas (basic science, clinical care, educational interventions, social science, epidemiological) of research specific to ASD. As a result, RU is expected to become a cross-campus academic institute of excellence with regards to ASD and will be recognized as a research, clinical, educational, and public policy model for ASD nationally and internationally.

References:

¹Centers for Disease Control and Prevention. Prevalence of Autism Spectrum Disorder Among Children Aged 8 Years — Autism and Developmental Disabilities Monitoring Network, 11 Sites, United States, 2010. Morbidity and Mortality Weekly Report, Surveillance Summaries. March 28, 2014.63:2.

²Centers for Disease Control and Prevention. Prevalence of Autism Spectrum Disorders --- Autism and Developmental Disabilities Monitoring Network, 14 Sites, United States, 2002. Morbidity and Mortality Weekly Report, Surveillance Summaries. February 9, 2007. 56(SS01);12-28.

³<http://njlifesciencevendoralliance.org/wp-content/uploads/2013/12/20131203-Rutgers-Presentation-at-Annual-Procurement-Conference-November-13-2013.pdf> (Accessed on 4/24/2014)
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