The Autism & Neurodevelopmental Disorders (AND) Initiative at the George Washington University is an eminent example of our commitment to translating cutting-edge research into policy and practice. George Washington’s strategic position in the heart of the nation’s capital will enable the AND Initiative to garner national attention for its mission while serving those affected by neurodevelopmental disorders through collaboration with community partners and service providers.

Steven Knapp
President
The George Washington University
The celebrated scientist James Watson, one of the discoverers of the double helix structure of DNA, once wrote that the brain is “the most complex thing we have yet discovered in our universe.”

That was 20 years ago and the brain today remains, for the most part, every bit as perplexing. “The brain,” wrote Dr. Watson, “boggles the mind.”

At the George Washington University—and in our time—among the most vexing questions we face are where and how brain development goes awry, the missed connections and faulty wiring known as neurodevelopmental disorders. These include disorders like epilepsy, cerebral palsy, fragile X syndrome, and autism—a household name yet still a mystery.

We are digging to find its roots, but we’re also interested in what can be done better when autism and other neurodevelopmental disorders emerge. What do people need from physicians, from therapists and educators, from policymakers to better treat these conditions and improve the lives of our children and young adults?

To us, it’s increasingly clear that the answers will be reached when we put our heads together; when we confront these issues from all angles. The time to do that is now, and the place to do it is GW.

We’re establishing a world-class Autism & Neurodevelopmental Disorders Initiative in collaboration with our affiliates, Children’s National Medical Center, Medical Faculty Associates and the George Washington University Hospital as well as area service providers. It’s where state-of-the-art medicine, research and support services for people with these disorders will join forces with something that GW is uniquely positioned to provide: real capacity for impacting policy.

“Washington” is our middle name. Our professors regularly are called upon to testify before Congress and provide insights, just as the president of the United States, his cabinet secretaries and other world leaders regularly appear on our campus—mere blocks from the White House—for major addresses and events.

GW also is home to the only school of public health in the nation’s capital. The nature of this Initiative, however, is deeply interdisciplinary. It has the potential to draw strength from every school on campus, without exception, creating a constellation of expertise.

The impact of this Initiative, we believe, will be felt not just in the nation’s capital but perhaps the world; not just in science and practice, but in the daily lives of millions.

Leo M. Chalupa
Vice President for Research
The George Washington University
What is Autism?

Autism was first diagnosed in 1943 by Dr. Leo Kanner; approximately 70 years ago. Autism is derived from the Greek words “autos” meaning self and “ism” meaning state or condition. Autism is a lifelong developmental disorder typified by difficulties with communication skills, trouble with social interactions and obsessive interests or repetitive behaviors. Due to these challenges, many people with autism may not engage with their family and/or their environment—staying to themselves, thus the root word “autos” in autism.

The term “autism” is used broadly to refer to neurodevelopmental disorders that fall along the autism spectrum (Autism Spectrum Disorder, ASD)—a group of similar disorders with a broad range in severity and include the most severe classic autism, a milder form known as Asperger syndrome and PDD-NOS, or pervasive developmental disorder—not otherwise specified. There is no medical diagnostic test for autism; diagnosis is currently determined by a group of observational and performance tests. Autism is found around the world and has no social, economic or cultural boundaries. While there is no known cause or cure for autism, early diagnosis and intervention have proven to greatly reduce severity and improve outcomes for affected individuals. Knowing this, pediatricians are asked to conduct a screening for autism during a child’s 18 and 24 month wellness check-ups and researchers are trying to develop more definitive tests that can alert clinicians to risks for ASD even earlier. Early detection and interventions are key.

Individuals with autism may have other co-existing neurodevelopmental disorders, such as learning differences, attention deficit hyperactivity disorder, anxiety, speech problems, seizures and epilepsy. For example there is a very high prevalence for an individual to have both autism and epilepsy and in some incidences, learning differences may be present as well. Research is the key to discovering why children may be faced with more than one challenge. Children with more than one neurodevelopmental disorder have a much more complex need for care and support which can have a very strong emotional and financial impact for a family and their community.

What are Neurodevelopmental Disorders?

Neurodevelopmental disorders are manifested when the development of the brain and/or central nervous system is compromised. Neurodevelopmental disorders are usually lifelong and may affect an individual’s cognitive capabilities, physical abilities and social interactions.

There are many known causes of neurodevelopmental disorders, such as genetics, fetal exposure to toxins, infectious diseases, immune disorders, nutritional deprivation and others. As with autism, an individual can have more than one neurodevelopmental disorder.

Neurodevelopmental disorders can include:

- Epilepsy
- DiGeorge syndrome
- Fragile X
- Tuberous sclerosis
- Neurofibromatosis
- Rett syndrome
- Childhood disintegrative disorder
- Down syndrome
- Cerebral palsy
- Chromosome 15 duplications
- Attention deficit hyperactivity disorder, etc.
HOW PREVALENT IS AUTISM?

In March 2012, the U.S. Centers for Disease Control and Prevention estimated the prevalence of autism spectrum disorders among U.S. children to be 1 in 88, 1 in 54 for boys.

Prevalence statistics have spiked in recent years, reflecting a 10–17 percent annual increase and an overall increase in diagnosis of 78 percent since 2002.

Today, there are more than 11,000 children with autism in the District of Columbia, Maryland and Virginia, 1.5 million children and adults with autism in the United States and an estimated 67 million children and adults with autism around the world.

More children will be diagnosed with autism this year than AIDS, diabetes and cancer – combined.

WHAT ARE THE COSTS?

- **$3.2 million**
  - The average cost for a lifetime of services for an individual with autism.

- **$137 billion a year**
  - Approximate total of autism expenses across the nation.

- **2/3 cost reduction**
  - For early diagnostics and interventions.

These documented increases in prevalence as well as enormous emotional impact and lifetime cost for families and society as a whole require immediate and focused attention to finding solutions.

SOURCE: AUTISM SPEAKS, AUTISM SOCIETY OF AMERICA

What is GW’s Solution?

**AUTISM NEURODEVELOPMENTAL DISORDERS INITIATIVE**

Focus will be on Research, Policy and Treatment

The AND Initiative will provide state-of-the-art assessments, interventions, medical treatments and support services related to autism and neurodevelopmental disorders as well as opportunities to participate in cutting-edge basic biomedical research, cognitive neuroscience research and clinical trials for individuals with autism and neurodevelopmental disorders. In addition, the policy arm of the initiative will conduct public policy analysis and educate policymakers and the public on issues related to autism and neurodevelopmental disorders, such as funding, early developmental screening, effective intervention, translating research to policy, income support, health and healthcare access disparities and lifelong services for people with autism and/or neurodevelopmental disorders.
The George Washington University, in collaboration with our affiliate hospitals and community service providers, will establish a world-class, interdisciplinary institute to address autism and neurodevelopmental disorders—the only one of its kind in the metropolitan area.

From GW’s Foggy Bottom campus, in the heart of the nation’s capital, this endeavor will serve individuals and their families as a one-stop resource for state-of-the-art assessments, interventions, medical treatments, support services and opportunities to participate in cutting-edge research.

The AND Initiative will be a beacon for policymakers, members of the media and the general public seeking information on issues surrounding policy, research and the treatment of autism and neurodevelopmental disorders.

With no known cause, preventative measures, medical detection or cure for autism, the time to act is now. The documented increase in prevalence as well as the enormous emotional impact and lifetime costs to families and society as a whole require immediate and focused attention to this growing problem.
Disorders (AND) Initiative

The AND Initiative will apply a multidisciplinary and interactive approach to

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<th>RESEARCH</th>
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<tr>
<td>Clinical care physicians and scientists will work together to conduct</td>
<td>There’s a great need for public policy that will streamline and</td>
<td>In the absence of medical diagnostic tests, clinicians currently diagnose</td>
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<td>comprehensive, collaborative research to bring a better understanding of</td>
<td>make affordable the necessary services for people with autism and</td>
<td>autism by observing a child’s behavior, communication and overall</td>
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<td>neurodevelopmental disorders, their prevalence in coexisting disorders</td>
<td>neurodevelopmental disorders.</td>
<td>development. It has been determined that early diagnosis,</td>
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<td>and ultimately solutions for the most effective treatments. Research</td>
<td>The Initiative will conduct research and analysis – from health</td>
<td>specialized education and behavioral therapies result in the best</td>
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<td>will include behavioral, evolutionary, systems, genetic, cellular and</td>
<td>insurance coverage to special education services for both children</td>
<td>outcomes for treating individuals with autism. The Initiative will</td>
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<td>core research support for molecular and cellular approaches to</td>
<td>and adults.</td>
<td>research treatments for core symptoms of autism and neurodevelopmental</td>
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<td>neuroscience to uncover underlying causes for autism and other</td>
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<td>neurodevelopmental disorders.</td>
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<td>cultivation of the strengths and talents of these individuals as they</td>
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<td>The Initiative will:</td>
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<td>transition from childhood to adulthood and seek educational training,</td>
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<td>▶ Conduct scientific research that illuminates the underpinnings of</td>
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<td>▶ Research a molecular diagnostic test for autism as well as genetic</td>
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<td>sub-types of autism; and</td>
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<td>▶ Translate findings into new therapies and approaches to treatment.</td>
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The Initiative will:

▶ Become a hub of information on autism and other neurodevelopmental      |
  disorders for policymakers, the media and the public;                   |
  
▶ Conduct timely analyses of public policies and provide policymakers,  |
  public health officials, health care administrators and advocates with  |
  the information and ideas they need to improve access to quality and   |
  affordable care; and                                                    |

▶ Forge partnerships to further explore policy issues of regional and    |
  national relevance.                                                    |

The Initiative will:

▶ Make breakthroughs in the way autism and other neurodevelopmental      |
  disorders are assessed;                                                |

▶ Bring autism into the age of personalized medicine with custom        |
  treatments based on an individual’s genetic sub-type of autism and their |
  specific needs; and                                                    |

▶ Provide interventions and services that address individual needs,     |
  from infancy through adulthood, in areas such as communication, social  |
  skills, learning and behavior.
How Will the AND Initiative Operate?

The new Initiative, following a five-year strategic plan, will leverage a multidisciplinary wealth of expertise—spanning the basic and social sciences, medicine, education, law, economics and health policy within the colleges at the university—and within the well-established, specialized entities. These include:

- The Clinical and Translational Science Institute at Children’s National Medical Center (a joint effort with GW that is part of a renowned, National Institutes of Health-funded consortium)
- GW Institute for Neuroscience
- GW Mind-Brain Institute
- GW Institute for Biomedical Sciences, the doctoral program track in neuroscience
- GW Speech and Hearing Center, providing a full range of speech, language and hearing services for all ages
- Secondary Special Education and Transition Services master’s program
- GW Early Childhood Special Education program
- GW Department of Counseling and Human Development
- GW Department of Health Policy
- GW Center for Health Policy Research
- On-going interactions with Medical Faculty Associates (MFA), the George Washington University Hospital and Children’s National Medical Center for clinical trials and pediatrics
Why George Washington?

The George Washington University is launching the AND Initiative from a solid foundation of established strengths in research, treatment and policy. GW is listed as a top-tier research school by the prestigious Carnegie Classification of Institutions of Higher Education. National Science Foundation (NSF) has ranked GW in the Nation’s top 100 research institutions in fiscal year 2010, US News and World Report ranked GW #50 in the nation recognized for undergraduate majors, master’s and doctoral degrees as well as committed to producing ground breaking research. In the 2012 Princeton Review evaluating the 373 top colleges, GW ranked as third in the nation for “Most Politically Active Students.” GW’s hard earned and accumulated recognitions reflect dedication to scholarship, research and leadership as well as the ability to achieve success in these endeavors.

GW faculty have demonstrated their interest through publications, presentations and researching autism and/or neurodevelopmental disorders in the areas of (but not limited to):

- Systems biology of ASD including functional genomics and bioinformatics
- Mouse models of gene-behavior relationships pertinent to neurological disorders
- Developmental neurobiology
- Research to discover markers that could be used to screen or diagnose autism
- Epidemiology and cross-cultural studies in ASD
- Cognitive development, including executive function and comparative cognition
- Pediatric neuroimaging (MRI) of autistic and neurotypical subjects
- Special education with a focus on developmental disorders
- Public policy issues, including screening, intervention, disparities and financing

WHY NOW?

Currently, there is no comprehensive institution in the DC metropolitan area that brings together expertise in public policy, research, diagnostics, intervention, education and treatment in the search for answers applicable to autism and neurodevelopmental disorders.

The AND Initiative is a top priority for the George Washington University and comes with a commitment to the future of science and engineering. It is GW’s aspiration to become this comprehensive institution, serving the needs of those affected throughout their lifespan, and in all areas of need including:

- Critical need to efficiently and effectively translate new biomedical research findings to experimental therapeutics and alternative treatments.
- Pressing need to help individuals and families navigate the labyrinth of educational, treatment, intervention and service options that are available to address the different needs of the autism population.
GW’s Vision for the AND Institute

The overarching goal is to launch an Autism & Neurodevelopmental Disorders Institute where the efforts, contributions and impact of the work performed will benefit individuals with autism and/or neurodevelopmental disorders and their families and earn national and international prominence in the areas of research, treatment and policy. Given our location in the heart of the nation’s capital and existing strengths in research, publications, treatment, public policy and governmental affairs, the AND Institute will also serve as a beacon for policymakers, media awareness efforts and the public concerning all autism and neurodevelopmental disorders related research, treatment and policy issues.
The George Washington University has always had a commitment to helping our world become a better place. I believe that this commitment is growing even stronger as we embark on a number of innovative initiatives such as the AND Institute.

The Institute builds on existing academic strengths at GW and adopts a progressive, interdisciplinary approach. It is well positioned to become a leader in the field of autism and neurological development, expanding knowledge and educating leaders in this important field.

Steven Lerman
Provost
The George Washington University
MISSION STATEMENT

The AND Institute will provide state-of-the-art assessments, interventions, medical treatments, support services related to autism and neurodevelopmental disabilities and opportunities to participate in cutting-edge basic biomedical research, cognitive neuroscience research and clinical trials for individuals with autism and neurodevelopmental disabilities. In addition, the policy arm of the Initiative will conduct public policy analysis and educate policymakers and the public on policy issues related to autism and neurodevelopmental disabilities, such as funding, early developmental screening, effective intervention, translating research to policy, income support, disparities and lifelong services for people with autism and/or neurodevelopmental disabilities.

Learn more about the AND Initiative by visiting us on the web:
http://research.gwu.edu/institutional-initiatives