Introduction

Two decades ago, autism was a little known, uncommon disorder. Today, with prevalence estimates increasing at an alarming pace, autism is emerging as a national health emergency. Autism is now recognized as a group of syndromes denoted as autism spectrum disorder (ASD). The most recent Centers for Disease Control and Prevention (CDC) prevalence estimates of ASD for children are 1 in 110 (CDC, 2009). These estimates, more than ten-fold higher than two decades ago, raise several urgent questions: Why has there been such an increase in prevalence? What can be done to reverse this alarming trend? How can we improve the outcomes of people already affected, including youth and adults?

Approaches to ASD diagnosis have evolved as more has been learned about the disorder. Currently, ASD is diagnosed on a combination of behavioral characteristics of impairment in verbal and nonverbal communication skills and social interactions, and restricted, repetitive, and stereotyped patterns of behavior, and these can range in impact from mild to significantly disabling. Adequately addressing these conditions requires sophisticated educational and therapeutic approaches. Some people with ASD also have a range of medical conditions including, but not limited to: motor and sensory impairments, seizures, immunological and metabolic abnormalities, sleep problems, and gastrointestinal symptoms.

The cost of ASD to affected people, families, and society is enormous. A great majority of adults with ASD struggle with ongoing and mostly unmet needs for employment, housing, services, and supports. Compounding these stressors, families with a child with autism typically lose income, possibly as a result of one parent leaving the workforce in order to care for and meet the special health and educational needs of the child (Montes & Halterman, 2008). The cost to society of ASD is currently estimated to be $35-$90 billion annually, the higher estimate being comparable to Alzheimer's disease (Ganz, 2007; Järbrink & Knapp, 2001). Although research on ASD has expanded over the past decade, there remains an urgent need for continuing research support.

It is imperative that resources be devoted to research commensurate with the public health need. Specifically, we need research that deepens our understanding of ASD, including the complex genetic and environmental factors that play a role in its causation; development of improved ASD diagnostic approaches and treatments; and science to enhance the level of services and supports available to people with ASD, their families and caregivers. With current scientific knowledge and tools, we have unprecedented potential for discoveries that will improve the quality of life for people with ASD.

In response to the heightened societal concern over ASD, Congress passed the Combating Autism Act (CAA) of 2006 (P.L. 109-416). Through this Act, Congress intended to rapidly increase, accelerate the pace, and improve coordination of scientific discovery in ASD research. The CAA requires the Interagency Autism Coordinating Committee (IACC) to develop and annually update a Strategic Plan for ASD research, including proposed budgetary requirements.

Driven by both the sense of urgency and a spirit of collaboration, the IACC developed an initial Strategic Plan for ASD Research in 2009 and revised it in 2010 in accordance with the CAA. The Plan and its revisions were developed through extensive and iterative input from members of the public, academic, and advocacy communities. In developing and revising the Strategic Plan, the IACC:

- Identified recent investments and accomplishments in ASD research.
- Assessed the strengths, weaknesses, opportunities, and gaps in the ASD research enterprise.
- Gathered ideas for research opportunities from a diverse group of stakeholders.
- Convened four scientific workshops and solicited input from the public and non-government research sponsors to identify research opportunities.
- Convened expert workgroups to recommend research objectives and strategies.
- Convened programmatic and agency experts to develop and recommend professional judgment budget estimates for each objective in the Plan.
- Convened a scientific workshop to review and revise the Strategic Plan in 2009.

The Strategic Plan incorporates this array of input in two main sections. First, the foundation of the Plan – vision, mission, core values, and crosscutting themes – is described. The remainder of the Plan is organized around seven critical questions asked by people and families living with ASD.

- **When should I be concerned?**
- **How can I understand what is happening?**
- **What caused this to happen and can this be prevented?**
- **Which treatments and interventions will help?**
- **Where can I turn for services?**
- **What does the future hold, particularly for adults?**
- **What other infrastructure and surveillance needs must be met?**

Each question is followed by a brief discussion of what we currently know and need from research, an aspirational goal, research opportunities and objectives. This framework was chosen by the IACC to emphasize the need for consumer-focused research that addresses the most pressing questions of people and families living with ASD, and to link these questions to specific research efforts.

Vision Statement

The Strategic Plan will accelerate and inspire research that will profoundly improve the health and well being of every person on the autism spectrum across the lifespan. The Plan will set the standard for public-private coordination and community engagement.

Mission Statement

The purpose of the Strategic Plan is to focus, coordinate, and accelerate high quality research and scientific discovery in partnership with stakeholders to answer the urgent questions and needs of people on the autism spectrum and their families.

Core Values

The IACC adopted these core values and emphasized their importance for the Strategic Plan development and implementation:

Sense of Urgency – We will focus on what steps we can take to respond rapidly and efficiently to the needs and challenges of people and families affected by ASD.

Excellence – We will pursue innovative basic and clinical research of the highest quality to protect the safety and advance the interests of people affected by ASD.

Spirit of Collaboration – We will treat others with respect, listen to diverse views with open minds, discuss submitted public comments, and foster discussions where participants can comfortably offer opposing opinions.

Consumer-focused – We will focus on making a difference in the lives of people affected by ASD, including people with ASD, their families, medical practitioners, educators, and scientists. It is important to consider the impact of research on the human rights, dignity, and quality of life of people with ASD from prenatal development forward.

Partnerships in Action – We will value cross-disciplinary approaches, data sharing, teamwork, and partnerships with clearly defined roles and responsibilities.

Accountability – We will develop SMART (Specific, Measurable, Achievable, Realistic, and Time-bound) research objectives aligned with funding priorities and develop systems for evaluation, assessing impact, and course corrections.

Crosscutting Themes

The Strategic Plan for ASD Research is designed to highlight the most promising research ideas, while appreciating the inherent unpredictability of research. These ideas form the basis for the research opportunities and objectives of the Strategic Plan. In the process of gathering ideas from ASD stakeholders for this Plan, certain themes emerged repeatedly. These themes are highlighted here to emphasize their importance across the framework.

Heterogeneity: Although certain core features are present at varying degrees among all people with ASD—i.e., social impairments, communication difficulties, and stereotyped behaviors—considerable heterogeneity exists as well. In the context of ASD, the term heterogeneity refers to the constellation of behavioral and medical conditions and symptoms that may accompany the disorder. The spectrum includes people with ASD who are nonverbal and cannot live independently, and others who find gainful employment and live independently. There is little reason to assume that this spectrum identifies a single disorder. Rather, the spectrum encompasses a range of disorders. The heterogeneity of ASD poses both challenges and opportunities to researchers: challenges, because there are likely to be many different causal factors and trajectories for ASD subtypes, and opportunities, because recognition of the variety of ASD phenotypes can lead to more appropriate diagnosis, more precisely targeted treatments, and increased public awareness about the diversity inherent in ASD. Heterogeneity has a profound impact on the priorities and tactics of ASD research, because any given study must either focus on a particular focal point on the spectrum, or must be sufficiently complex and resourced to encompass a broader range along the spectrum. Acknowledging heterogeneity also has implications for intervention. With multiple causes and symptoms, there likely will be multiple ways and approaches to intervene (e.g., medical, behavioral, nutritional). In so doing, the ASD field will be more strategically positioned to determine what works best for which people.

Prevention: It is critical for research to identify the methods and approaches that can be used to prevent the challenges and disabilities of ASD. Additionally, if one views ASD as a biological disorder triggered in genetically susceptible people by environmental factors, then prevention can include prevention of new cases of ASD through the identification and elimination of environmental causes. What is essential for ASD research is to develop the state of knowledge to a level similar to what is now available in fields such as cardiology. No longer do we need to wait for someone to suffer a heart attack before providing life-saving treatments. Rather, early interventions are applied upon the detection of risk factors so as to preempt these more serious consequences. Having sound research on the risk factors and the environmental triggers for ASD ultimately may allow us to achieve the goal of prevention: preventing the development of the disorder in some people at risk or reducing the degree of severity in those affected.

Earlier Detection: ASD is a developmental brain disorder that is currently diagnosed by the observation of core behavioral symptoms. As with many neurodevelopmental disorders, brain dysfunction may precede abnormal behavior by months or even years. However, without biomarkers to detect people either with or "at risk" for ASD during pre- or neonatal periods, diagnosis must rely on behavioral observations long after birth. As a result, intervention efforts may miss a critical developmental window. Until recently, most children with ASD in the United States (U.S.) did not receive a diagnosis until school age, and diagnosis was further delayed among disadvantaged or rural populations (Mandell et al., 2007). It is critical that the field enhance methods for detecting ASD earlier in life and across diverse populations, in order to bring about earlier intervention. Furthermore, a recurrent theme expressed during the scientific workshops for the Plan was the need for biomarkers to identify ASD risk before the behavioral manifestations and the delayed developmental trajectory are established.

Lifespan Perspective: Historically, ASD has been characterized as a disorder of childhood. Although most people with ASD will not outgrow their diagnosis, their symptoms will change in form and severity over time. There was great support during the development of this Plan for more research on ASD in older people, especially the need for practical strategies for increasing the quality of life and functioning of adolescents and adults with ASD. As people with ASD advocate for themselves and expand our knowledge of their experiences and needs, they become partners in the research effort.

Data Sharing: Data sharing allows researchers to: (a) validate the research results of other investigators; (b) pool standardized information collected by many different researchers to facilitate rapid progress; and, (c) use data collected by others to explore hypotheses not considered by the original investigators. The expectations for data sharing have increased with the recognition that larger samples are needed to answer many research questions and with the sense of urgency for making progress. Databases for neuroimaging scans and genomic sequence are already proving important for ASD research. Wide adoption of a standardized data sharing system like the National Database for Autism Research (NDAR) can provide the necessary infrastructure to combine important research participant data and thereby propel ASD research forward.

Resources: In addition to data sharing, research often depends on the availability and quality of research resources, such as access to scientific instruments and repositories of biospecimens. An important resource, paradoxically, is the identification, assessment, and collection of biospecimens from people who do *not* have the disorder, as a basis for comparison. Such comparison groups serve a critical role in interpreting ASD research and findings. Moreover, human resources such as adequate numbers of well-trained researchers and administrators are vital to these efforts. This need cannot be understated. Attracting a cadre of rigorously trained researchers, including those outside the ASD research field, will foster innovative ideas and inter-disciplinary approaches**.**

Public-Private Partnerships: A strength of current ASD research is the degree of private involvement and investment in research funding from advocacy groups and committed stakeholders. In addition, the amount of research dollars awarded by the U.S. government for ASD research has grown rapidly over the past ten years. There is currently a great willingness on the part of government agencies and private organizations to collaborate on the development and implementation of the Strategic Plan for ASD Research. In fact, the Strategic Plan is built on the premise that the public and private sectors will work collaboratively to better leverage resources to advance the research opportunities and objectives put forth in the Plan.

Community Engagement in ASD Research: People with ASD, their families, their educators, their caregivers, and advocacy organizations have vital roles to play in shaping, participating in, and disseminating research. Their insights and perspectives are needed in order for interventions and services to be developed that will have maximal impact and have the strongest evidence and means for real-world uptake and utilization. Strategies are needed to gain and use the first-hand experience of people with ASD, their families, and caregivers.