

February 15, 2018

Diana W. Bianchi, M.D.
Director
Eunice Kennedy Shriver National Institute of Child Health and Human Development

Dear Dr. Bianchi:

On behalf of the Association of University Centers on Disabilities (AUCD), we thank you for the opportunity to offer commentary on the National Institute of Child Health and Human Development (NICHD) Draft Strategic Plan. We applaud NICHD's efforts to address the wide array of emerging and long-standing challenges that threaten to erode gains in public health. But lacking within the plan itself is the recognition of a *growing* need for investment into research on disability, and the promise of transformational developments from research to impact the lives of people with disabilities.

NICHD was formed with a foundational commitment to research on disability, including intellectual and developmental disability (IDD). In 1962, Congress established NICHD within the National Institutes of Health (NIH) to investigate human development at all its stages, from preconception to adulthood, including IDDs and events of pregnancy. For more than five decades, NICHD has provided both national and international leadership for research involving people with disabilities. In the fields of developmental biology, reproductive health, child development, pediatrics, population health, and medical rehabilitation, the institute's research portfolio has included:

- Basic research, which tests theories to examine underlying physiological mechanisms to understand disability;
- Applied research, which examines a specific set of circumstances that have real world application.

The numbers and needs of people living with disabilities in the United States and the global community continue to be influenced by a complex set of challenges. At the same time, technology breakthroughs – whether in genome sequencing, artificial intelligence, mobile devices or other fields – offer new opportunities for scientific discovery and advancements in health and wellbeing for people with disabilities. NICHD must remain committed to leveraging its well-positioned resources to accelerate the basic, applied, translational and clinical science needed to address these growing challenges and to optimize the quality of life for people with disabilities.

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Given its foundational priorities, we urge NICHD to include the following changes into its strategic plan:

•Ensure that individuals with disabilities and their family members are direct and active participants at every phase of research focused on disability issues, including health research.

Family members are the backbone of caregiving, and their capacity for advocacy is surpassed only by individuals with disabilities themselves. Engagement must go beyond basic inclusion, and their voices should be integrated into discussions defining research questions, modifying methods, collecting data, analyzing results, and knowledge translation. While this commitment to engagement significantly benefits the research process and products, it's not practiced consistently by researchers. We strongly suggest that disability engagement be included as part of the scoring rubric in determining funding decisions and making awards. This should include families who are racially, culturally and linguistically diverse.

•Expand efforts to improve developmental outcomes. This is the proud and historic legacy population of focus since NICHD's founding. Approximately 6.5 million people in the United States have an intellectual disability, with ID occurring in approximately 1-3 percent of the global population. While there have been many scientific advances, the 1-3 percent has remained relatively stable. However, the CDC has indicated an increase in prevalence of developmental disabilities in children and youth between 3 and 17 years of age, although this increase was attributed to developmental delays other than autism and intellectual disabilities. Again, continued efforts need to be made to improve developmental outcomes and implement evidence-based practice.

•Uphold NICHD's commitment to support the advancement of genomics and neuroscience, while considering ethical implications. Much research is being conducted on the treatment of rare genetic disorders and inborn errors of metabolism that historically have resulted in significant disability and/or death, which should continue. But where rapid advances in discovery and precision medicine have achieved impressive successes, there needs to be a concurrent dialogue with the individuals and families impacted by these victories. This sentiment links closely with the desired inclusion of people with disabilities in the research process. An open and sustained dialogue between the research and disability communities must be strengthened, not to slow innovation but to inform it. A shared understanding of both the goals and perspectives of scientists and people with disabilities will benefit both constituencies. NICHD has an excellent record of convening diverse viewpoints and can help facilitate this important dialogue.

AUCD has worked closely with our network partners in the IDDRC, UCEDD, and LEND programs to foster dialogue and conversation between researchers and the disability community. This has included panel discussions at our annual conference, as well as an extended session during the most recent IDDRC annual meeting. These 'safe spaces' have helped bridge differences in language and culture and provided valuable opportunities to learn from and about the priorities and concerns of each community.

In addition to ethical implications that impact individuals, the systemic response to such potential changes in the disability population or the prevalence of specific disabilities should be deeply considered in an intentional and informed manner.

•Continue to lead during this time of unprecedented scientific opportunities for new discovery in causes and treatments for disabilities. Individuals with disabilities, their family members, their communities and the global community are expectantly engaged in the potential of real breakthroughs that are poised to extend and enhance quality of lives. NICHD is uniquely positioned to lead these advances,

bridging basic and applied research in a way that translates into scientific advances that positively impact the lives of people with disabilities and their families.

We would also like to suggest an additional thematic area:

Research Theme #7: Improving Health Among Individuals with Intellectual and/or Developmental Disabilities

Goal: Improve health status and outcomes by preventing and managing chronic disease to enhance the quality of life among individuals with intellectual and/or developmental disabilities of all ages.

Opportunities: Compared with individuals without disabilities, individuals with intellectual and developmental disabilities are at higher risk for such chronic diseases as obesity, hypertension, diabetes, and depression. Yet, individuals with such disabilities are less likely to receive recommended preventive health care services and screenings. NICHD aims to identify those factors that contribute to poorer health status and outcomes in this population and that serve as barriers to access and underutilized health services.

This additional theme is wholly consistent with the current NIH-wide strategic plan for rehabilitation that was conducted and assembled by the National Center for Medical Rehabilitation Research.

Without NICHD's continued commitment to research in disability, what is ultimately at stake is a reversion to a lower quality of life for individuals with disabilities as well as their families. We hope that the strategic plan will ultimately include robust support for disability research and are ready to contribute our assistance if it is required.

Sincerely,

A handwritten signature in cursive script that reads "Andrew J. Imparato". The signature is written in black ink and is positioned above the typed name and title.

Andrew J. Imparato, JD
Executive Director