

# INTELLECTUAL AND DEVELOPMENTAL DISABILITIES RESEARCH CENTERS

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To: Diana W. Bianchi, M.D., Director, *Eunice Kennedy Shriver NICHD*  
From: Directors of the Intellectual and Developmental Disabilities Research Centers  
RE: RFI Response, NICHD Strategic Plan

28 January 2019

Dear Dr. Bianchi:

We reviewed the RFI with great interest and wish to express both *gratitude* for the inspirational scientific vision that characterizes the document, and a *major concern* that it omits a coherent representation of ***intellectual and developmental disability*** as a distinct priority of the Institute's research agenda. Given that at least 1 in 6 individuals is affected by an intellectual or developmental disability, it is clear that this class of disorders represents a major public health and social challenge in the USA and beyond. Thankfully, progress made through support from NICHD has advanced the field to the point where we are now poised to have a major impact on this class of disorders if we continue to push the research to understand the mechanisms driving their various features and capitalize on exciting new therapeutic approaches. It is fair to say, that discoveries in neurodevelopmental disorders have had impact well beyond childhood disorders. Whether it is the principle of sporadic mutations causing genetic disorders, dynamic mutations causing disease, or pleiotropy (same gene causing either autism or schizophrenia), it all started in developmental disorders.

Translational advances in treating genetic disorders have become a reality though the study of intellectual and developmental disabilities—examples include disorders such as Down syndrome, Fragile X syndrome, Angelman Syndrome, Rett and *MECP2* duplication syndrome, Ceroid Lipofuscinosis—and the derivation of highly-specific therapies, such as Everolimus for epilepsy in Tuberous Sclerosis, and antisense oligonucleotides for spinal muscular atrophy. The time is now to continue investing in the understanding and treatment of this class of disorders that affect so many and impact society in more than one way. To do so will undoubtedly require integrated trans-disciplinary science, which is led and prioritized by NICHD to avoid the fragmentation that is typical of individually funded projects from distinct NIH institutes. We note, however, that neither theme #1, *Understanding Early Human Development*, nor theme #6 *Ensuring Safe and Effective Therapeutics and Devices*, explicitly reflect the strategic harnessing of recent scientific advances in genomics and neuroscience to address disorders of development—including autism, intellectual disability, and other disabilities—in order to prevent or ameliorate their impact.

We admire your efforts in the current strategic plan to clarify research priorities, and fully appreciate that the Institute cannot prioritize everything and will be most successful if its mission is focused on critical elements along the discovery frontier. In doing so, however, a comprehensive focus on intellectual and developmental disabilities research is lost, and ***it is our hope that it can be substantially restored in a revision to the Strategic Plan, on a par with representation of the public health priorities of infertility, women's health, and aging.*** This would ensure a domain of strategic prioritization that honors and makes actionable a set of spectacular scientific discoveries of the past decade, which collectively represent tangible new hope for a vast population whose future hinges on a next decade of progress supported by the Eunice Kennedy Shriver National Institute of Child Health and Human Development.

We, the undersigned IDDRC Directors, stand ready to contribute to a next era of discovery in which NICHD both leads and leverages the investment of all NIH Institutes in IDD investigation.

Respectfully,

*The Directors of the Intellectual and Developmental Disabilities Research Centers of the Eunice Kennedy Shriver National Institute of Child Health and Human Development*

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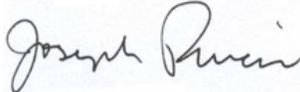
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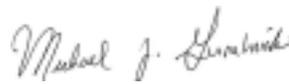
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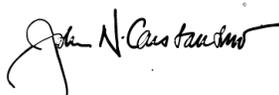
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