The Intellectual and Developmental Disabilities Center

Stanford Children's Health
Stanford Hospitals and Clinics

The Intellectual and Developmental Disabilities Center at Stanford University

Intellectual and developmental disabilities (IDD) represent a substantial source of morbidity and mortality among the U.S. population. Intellectual disability is characterized by significant limitations in intellectual functioning and adaptive behavior as expressed in conceptual, social, and practical life skills originating before age 18 years. Developmental disabilities are defined more broadly as severe chronic disabilities that can be cognitive, physical, or both, that generally appear before age 22 years, and that are likely to be lifelong. When identified using this broad definition, IDD is very common, occurring in about 1 in 6 individuals in the U.S.

A significant degree of clinical activity, education and training, and basic and applied research relevant to IDD already occurs throughout the Stanford campus. However, IDD-related expertise and talents at Stanford are currently dispersed.

The Intellectual and Developmental Disabilities Center's mission is to organize a cohesive infrastructure around IDD at the institutional level with the goal of making Stanford University a leader in discovery, translation, education, prevention and clinical service delivery. Through integrated and coordinated clinical care, research and professional training, Stanford can become a potent force and world leader in this field.

Inaugural Meeting of the IDD-C

On February 28th, 2014, the Intellectual and Developmental Disabilities Center (IDD-C) at Stanford University, lead by Dr. Allan Reiss kicked off efforts with an inaugural symposium, bringing together a panel of experts from the community and various departments of Stanford University School of Medicine. Attendees gathered at the Frances C. Arrillaga Alumni Center to hear featured speakers discuss current original research and potential implications for IDD populations. Material was formatted to PechaKucha 20x20, a presentation style originating in Tokyo wherein presentations are limited to 20 slides with each slide automatically advancing after 20 seconds, encouraging concise, cogent glimpses into the cutting-edge research currently being conducted across Stanford University.

Community perspectives were also represented. Executive director, Lynda Joyce Steele (cover, left) along with Sheraden Nicholau of Abilities United discussed the how their programs and partnerships with local schools and businesses have helped thousands of people with developmental and physical disabilities fully participate in community life. The Palo Alto based organization has been serving children and adults with disabilities for more than 50 years. With a unique point of view as parents, philanthropists, and former board members of the National Fragile X Foundation, Scott and Lynda Canel (cover, right) discussed the challenges facing individuals with IDD as they enter adulthood, touching on areas of need from housing and employment to relationships and spiritual life.

Finally, invited keynote speaker, Dr. John Constantino (cover, center), Professor of Psychiatry and Pediatrics at Washington University School of Medicine and Associate Director of the Intellectual and Developmental Disability Research Center (IDDRC) delivered a review of seminal work in the field with a lens on autism research. Critically, he provided a blueprint of the structure and triage of activity in the IDDRC, all towards elucidating causation and innovating intervention in IDD.

Featured Research

Lu Chen, PhD

Associate Professor of Neurosurgery and Psychiatry and Behavioral Sciences. Dr. Chen's research is dedicated to understanding the cellular and molecular mechanisms that underlie synapse function during development and how it is altered in neurological and neuropsychiatric disorders. She discussed her current research on synaptic dysfunction in fragile X syndrome and the role of FMRP in synaptic signaling.

Michael Lin, MD, PhD

Assistant Professor of Pediatrics and Bioengineering. Dr. Lin applies biochemical knowledge and engineering principles to the development of protein-based tools for molecular imaging, optogenetic studies, and gene therapy. He discussed the development of new optical tools for understanding neuronal function and plasticity and how they can aid in real time visualization of synaptic strengthening and electrical activity in the brain.

Alex Urban, PhD

Assistant Professor of Psychiatry and Behavioral Sciences and Genetics. Dr. Urban's research focuses on developing genomics analysis tools to study sequence variation in brain development and function. He explained his research in the genomic characterization of a panel of iPSC lines in 22q11 Deletion Syndrome to a better understand of the molecular etiology of this disorder.

Scott Hall, PhD

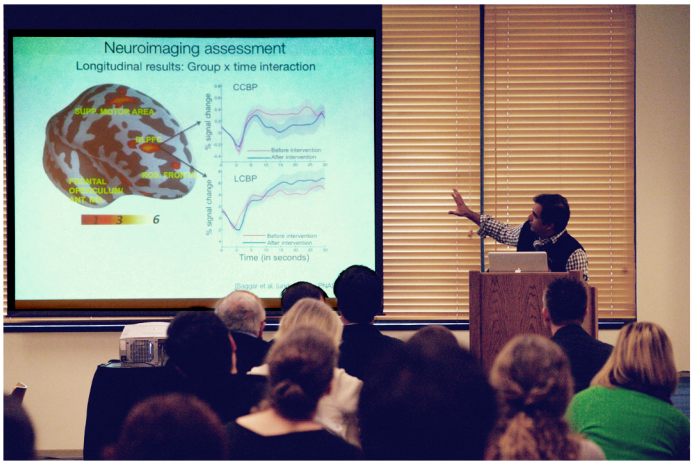
Assistant Professor of Psychiatry and Behavioral Sciences. Dr. Hall spoke about his research on understanding the pathogenesis of problem behaviors in children and adults with neurodevelopmental disorders. He uses interdisciplinary methods to examine the biological and environmental determinants of aberrant behavior, common in genetic disorders like fragile X and Prader-Willi syndrome.

David Hong, MD

Instructor of Psychiatry and Behavioral Sciences. Dr. Hong discussed the role of sex differences in learning disorders, which can provide important insights into neurobiological mechanisms underlying intellectual disability. Through the study of genetic conditions such as Turner and Klinefelter syndromes, Dr. Hong's research focuses on the contribution of sex chromosome effects to brain development and cognition.

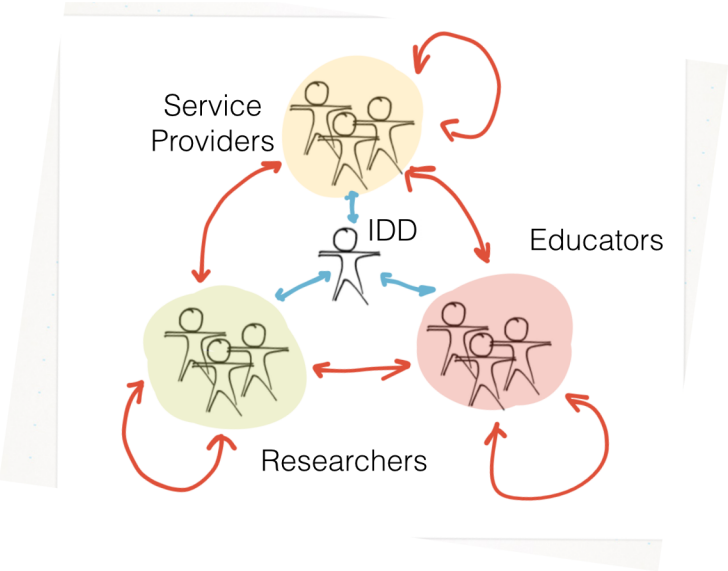
Manish Saggar, PhD

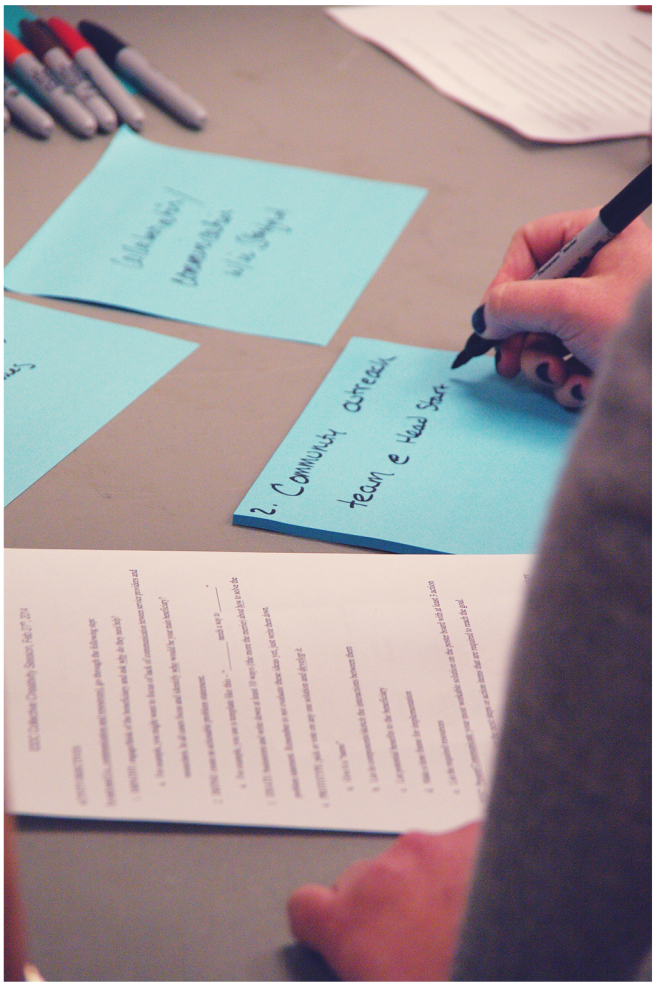
Postdoctoral Scholar in Psychiatry and Behavioral Sciences. Dr. Saggar, a computational neuroscientist, discussed his research on the neuroscience of enhancing creative capacity. His work has been applied to typically developing adults and persons with neuropsychiatric disorders and holds important implications for interventions in IDD populations.



IDD in 2020

The symposium concluded with a brainstorming session moderated by Dr. Manish Saggar. "We used design-thinking principles like need-finding, ideating, and rapid prototyping to create out-of-the-box solutions for improving communication between service providers, educators and researchers and for efficiently allocating community and educational resources" said Saggar. The exercise bred a host of exciting ideas involving the use of selected technologies to share information between stakeholders, the development of new community engagement opportunities for young research scholars at service delivery sites, and creative ways to make resources more accessible for underserved populations.





Administration

Allan Reiss, MD, Acting Program Director
Reiko Riley, MPH, Program Manager
Rebecca Barnett, MS, BCBA, Program Coordinator

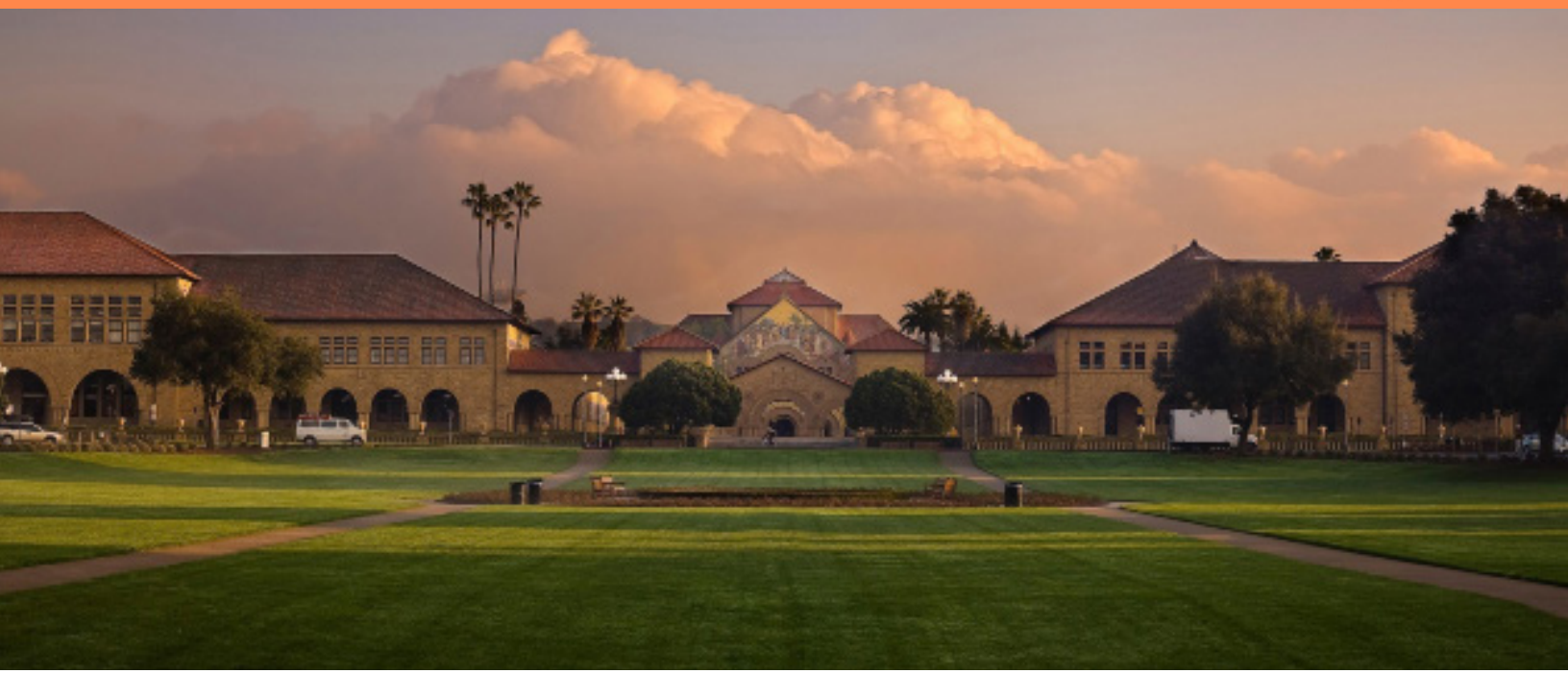
Special Thanks

In addition to the speakers, we extend special thanks to those people, departments, and organizations without whom, this event would not have been possible.

Gary Steinberg, MD, PhD
Stanford Institute for Neuro-Innovation & Translational Neuroscience

William Newsome, PhD
Stanford Neurosciences Institute

Laura Roberts, MD, PhD
Chair, Department of Psychiatry and Behavioral Sciences



Message from the Acting Director

The concept of an Intellectual and Developmental Disability Center (IDD-C) at Stanford arose from many years of clinical and research experience with children and families facing the complexities of care in intellectual and developmental disabilities. The concept of Stanford's IDD-C—a center that seamlessly spans existing medical departments, divisions and programs and integrates pediatric and adult interests in a lifespan approach—is intriguing, exciting, feasible, timely and necessary. As such, it can be a "game-changer" for Stanford.

Stanford is already known for being a leader in highly effective clinical programs and pioneering research. Thus, our institution is in a key position to create this enterprise. Through integrative research, new models of training and clinical care and bi-directional interaction with community, we seek to redesign the way in which services are provided to this population.

We welcome the ideas and contributions of all those who share in our vision and mission and look forward to working together to achieve it.

Stanford IDD News

Stanford given $7.2 million grant to join Undiagnosed Diseases Network

Guidelines for genome-sequencing tests for kids

Scientists tie social behavior to activity in specific brain circuit

New Stanford Medicine website launched

"Bold and game-changing" federal report calls for $4.5 billion in brain-research funding

Learning how we learn to read

The rechargeable brain: Blood plasma from young mice improves old mice's memory and learning

Partnership enables discoveries to move from bench to bedside

5 Questions: Ann Arvin on Stanford's history of collaboration