

Autism Data Privacy Advisory Group

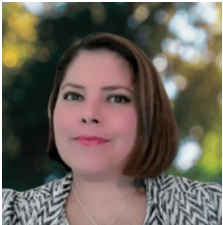
Appointed Members

The Autism Data Privacy Advisory Group provides recommendations to the Governor on guidelines to protect the civil and human rights of people with autism in Illinois (EO 2025-02)

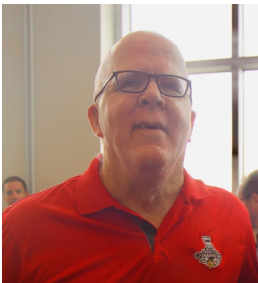
Appointed Members:



Kruti Acharya, MD, is a Developmental and Behavioral pediatrician and Associate Professor at the University of Illinois Chicago's Department of Disability and Human Development and College Medicine. In her clinical practice, she supports adolescents and young adults with developmental disabilities and their families as they transition to adult-systems of care. As a researcher, she focuses on ways to improve services and supports for individuals with disabilities across the lifespan. Dr. Acharya earned her MD from Boston University and completed the MacLean Fellowship in Clinical Medical Ethics at the University of Chicago. She lives in Northfield.



Ruth Aguilar, QIDP, is a Senior Ligas Family Advocate at The Arc of Illinois. She has over fifteen years of experience advocating for people with disabilities. Ruth's professional experience stems from working previously in an Independent Service Coordination Agency and then as a Self-Directed Assistant serving the community with intellectual and developmental disabilities. As the mother of a teen girl with Rett Syndrome and Seizure Disorder, Ruth brings a wealth of personal knowledge to the families she serves. She earned a BS in Psychology from the Illinois Institute of Technology and Professional Graduate Studies Certificate in Non-Profit Management from Harvard University. She lives in Chicago.



Mike Baker is a parent advocate for his son with autism. He has helped write, find sponsors for, pass, and get seven bills signed into law and 1 joint resolution to help people with autism and developmental disabilities in Illinois. These bills have included provisions which require insurers to cover dental anesthesia for people with developmental disabilities up to age 26 and increased training for caregivers through direct support professionals among other initiatives. He lives in Schaumburg.



Stephanie Brown is the President and Founder of the Autism Society of Southern Illinois, Illinois' only affiliate of the National Autism Society. She serves on the National Autism Society's Legislative Policy Committee, shaping national disability policy. Brown is an active disability advocate in Illinois, serving as a member of the Illinois Autism Taskforce, Chairperson of the Illinois Council for Developmental Disabilities, and Chairperson of the Human Relations Commissions for the City of Carbondale. Additionally, she is a Parent Educator and Supervisor for Rebound Family Literacy Program, providing developmental support and resources to families with young children. Brown earned her BA from Southern Illinois University. She lives in Carbondale.



Patricia M. Brown, JD, is Deputy General Counsel for the Division of Developmental Disabilities and Division of Rehabilitation Services at the Illinois Department of Human Services (IDHS). She provides comprehensive legal counsel on various aspects of program operations dedicated to serving people with disabilities in Illinois, including reviewing legislation, administrative rules, and policies. She also advises on matters related to confidentiality, privacy protection, and FOIA compliance. Pat previously served as the HIPAA Chief Privacy Officer for IDHS, where she managed complex privacy breach responses and reported to state and federal agencies on privacy matters. She earned her JD from DePaul University College of Law. She lives in Chicago.



Will Hrabe, JD, is Assistant Legal Counsel for the Illinois State Board of Education, where he focuses on the provision of special education services. He previously served as an Equal Justice Works Fellow and Staff Attorney for Equip for Equality. He earned his JD from University of Illinois College of Law. He lives in Chicago.



Kimberly Johnson is the Past President/Executive Director of Chicagoland Autism Connection and the Board President of The Arc of Illinois. She works as a Regional Coordinator (Cook County) for the Community Residential Services Authority, providing technical assistance to families, service providers, educators, and other professionals to help plan and implement services for children with severe emotional disturbance and/or behavior disorders. She is also a parent of an adult son living with Autism and Speech Language Disorder. She lives in Chicago.



Colin Killick, MPP, is the Executive Director of the Autistic Self Advocacy Network, a national grassroots disability rights organization run by and for autistic people. Prior to joining ASAN, he served as the Executive Director of the Disability Policy Consortium. Colin's work has covered a variety of disability rights issues, including founding an advocacy partnership that led to a 450% increase in state housing voucher funding for low-income people with disabilities. Colin earned his MPP from Harvard Kennedy School of Government. He lives in Washington, DC.



Clint Paul, MPA, serves as the President and CEO of Vision for Hope. Mr. Paul has driven Hope's strategic goals by focusing on the expansion of community-based and outpatient clinical programs, as well as providing oversight to the conversion from Hope's historic institutional housing to full community-based group homes. Hope now serves individuals with disabilities through their entire lives. Hope's impact has grown from less than 1,000 individuals in 2014, to well over 5,000 in 2021, and continues to grow every day. Mr. Paul is a Licensed Certified Public Accountant and earned his MPA from the University of South Dakota. He lives in Springfield.



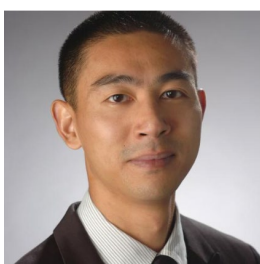
Dr. Jennifer Seo, MD, JD, is the Pediatric Medicine Medical Advisor at the Illinois Department of Public Health (IDPH). She previously served as the Chief Medical Officer for the Chicago Department of Public Health and the Chief Medical Officer for Christian Community Health Center. She earned her MD from Vanderbilt University School of Medicine and her JD from Columbia Law School. Dr. Seo lives in Chicago.



Helen Tager-Flusberg, PhD, is the Director of the Center for Autism Research and Excellence at Boston University where she is also Professor Emerita. She founded the Coalition of Autism Scientists. She serves as an invited member of the Federal Interagency Autism Coordinating Committee of HHS, a member of the Scientific Advisory Board of the Tan-Yang Autism Centers MIT & Harvard, and a member of the Scientific Advisory Committee of the International Society for Autism Research, among other positions. Dr. Tager-Flusberg earned her PhD in Experimental Psychology from Harvard University. She lives in Newton, Massachusetts.



Andy Shih, PhD, is the Chief Science Officer for Autism Speaks. Dr. Shih joined Autism Speaks in 2006 after its merger with the National Alliance for Autism Research, where he served as the Chief Science Officer. Dr. Shih was central to the 2008 passage of the World Autism Awareness Day resolution at the United Nations and subsequently led the development of the Global Autism Public Health (GAPH) initiative that provides technical support to country governments to enhance autism awareness, advocacy, research and services worldwide. Dr. Shih earned a PhD in molecular cell biology from New York University School of Medicine. Dr. Shih lives in the suburbs of New York City.



Yang Wang, PhD, is a professor in the School of Information Sciences at the University of Illinois at Urbana-Champaign. He co-directs the Social Computing Systems (SALT) Lab. He was previously an assistant professor in the School of Information Studies at Syracuse University and a research scientist in CyLab at Carnegie Mellon University. His research is centered around usable privacy and security, and social computing. His work has appeared in news media such as *The New York Times*, *Wall Street Journal*, BBC, and China Daily. Dr. Wang earned his PhD in information and computer science from the University of California, Irvine. He lives in Champaign.