



You're invited to our inaugural POLICY SUMMIT

on

IMPROVING THE LIVES OF PEOPLE WITH INTELLECTUAL AND/OR DEVELOPMENTAL DISABILITIES AND CO-EXISTING MENTAL CONDITIONS

November 30, 2022

9 am – 3 pm

Empire State Plaza Meeting Rooms 3 & 4

(Lunch will be provided)

You're invited to be **OUR GUEST** at this summit because we value your experience, knowledge, personal familiarity, advocacy for change, leadership, stakeholder role, and empathy.

This conversation was initiated by the Cerebral Palsy Associations of New York State (CP State), Mental Health Association in New York State, Inc. (MHANYS), and New York Association of Psychiatric Rehabilitation Services, Inc. (NYAPRS) to bring to the forefront attention on the call from the disability community to address multiple and growing issues related to diagnosis, access to care, treatment modalities, and follow-up care with mental health services.

The policy paper [At The Crossroads: People with Intellectual and/or Developmental Disabilities \(I/DD\) and Co-existing Mental Conditions](#) summarizes the results of a series of listening sessions with statewide affiliates organized by CP State that capture the reality of these claims in first-person accounts. The hallmark theme is a collaborative plan for positive change.

In addition to hearing from speakers who offer their professional and clinical perspectives as well as personal views on the emerging crisis in this area, the summit will also include a special panel discussion with the Honorable Kerri Neifeld, Commissioner of Office of People With Developmental Disabilities and the Honorable Ann Sullivan, Commissioner of Office of Mental Health on their agencies' commitment to addressing the issues highlighted in the paper.

Summit participants will be able to share their reactions, experiences and views in regional roundtable sessions that will be used to guide for discussion with the two Commissioners in their session.

There is limited space available and we'd be honored to see you at the summit, so please register using this [LINK](#) by **November 11, 2022 to secure your spot.**

Further details will be provided.

Mike Alvaro
President & CEO
CP State

Glenn Liebman
CEO
MHANYS

Harvey Rosenthal
CEO
NYAPRS

For questions, please call (518) 436-0178.



OVERVIEW

AT THE CROSSROADS: People with Intellectual and/or Developmental Disabilities (I/DD) and Co-existing Mental Conditions¹

This paper was written in response to an urgent cry from the disability community to address multiple and growing issues related to diagnosis, access to care, treatment modalities, and follow-up care with mental health services. The results of a series of listening sessions with statewide affiliates that were organized by the umbrella organization, Cerebral Palsy Associations of New York State (CP State), capture the reality of these claims in first-voice accounts. The hallmark theme is a plan for positive change.

The findings are collapsed into four categories that naturally emerged from the session: 1) distinguishing mental conditions and disabilities; 2) diagnosis, care and treatment of co-existing mental conditions; 3) crisis mental health care; and 4) suicide awareness and prevention. Each category is followed with a brief account of what the literature tells us and followed by a series of policy recommendations that collectively depict the organization, financing and delivery of services.

Expressed recognitions that the liberal use of the term “behavioral health” does not include people with I/DD sets the backdrop for other issues, including diagnostic overshadowing, assumptions about treatment decisions, and need for educational programs about mental health, wellness, and wellbeing.

Health disparities, education across professional disciplines, and workforce shortages cross all categories. Telehealth services, video and/or audio services where available, did not routinely include mental health providers. This was attributed to funding issues and shortage of psychiatrists.

A section of the paper relating to crisis and suicide is disquieting. Here, revelations highlight a broad breakdown at all system levels to address the complexities of caring for people with multiple conditions. The cyclic nature of crisis care and repeated failure to address this is not new and is now a common but under-studied problem. Closely aligned is the incidence of suicide, which is and not talked about in people with I/DD. Suicide in people with I/DD happens. There is a critical need for educating all staff about suicide and suicide prevention strategies.

CP affiliates have provided information that singly or collectively could “delay” or “prevent” a person with co-existing Intellectual Developmental Disabilities and Mental Conditions from being adequately treated both in community settings, emergency departments and hospital inpatient settings. Ultimately, this could cause harm or even death. This is particularly evident from the affiliates’ accounts of staff shortages, inadequate support for direct support staff, deficient education for primary care doctors and psychiatrists, and the cyclic nature of emergency care. We are standing at the crossroads, and we are at the point of “no return” and call upon all state and local partners to support a planned concerted effort to move forward.

¹ AT THE CROSSROADS: People with Intellectual and/or Developmental Disabilities (I/DD) and Co-existing Mental Conditions. June 2022. Sharon Carpinello, Ph.D., R.N. & Mike Alvaro, President & CEO of Cerebral Palsy Associations of New York State.