Cerebral Palsy Associations of New York State

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June 2022

CP of NYS POLICY RECOMMENDATIONS

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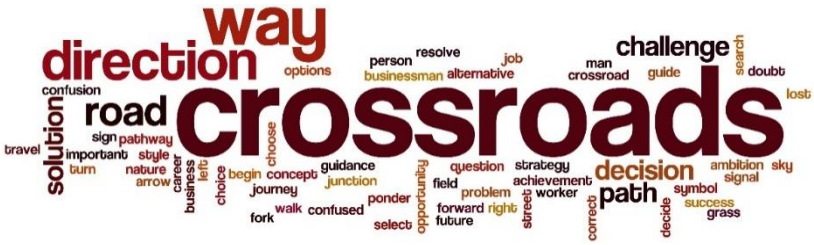
At The Crossroads:

People with Intellectual and/or Developmental Disabilities (I/DD) *and* Co-existing Mental Conditions

INTRODUCTION

Cerebral Palsy Associations of New York State was founded by families almost 80 years ago to provide community supports and services, when none were available, for people with intellectual and developmental disabilities (I/DD). Over the years, the CP Affiliates developed an expertise in providing clinical and other supports to meet the needs of the whole person. With that practical experience, our Affiliates have witnessed a growing percentage of the patients in our clinics, residents in our homes, and participants in our other programs who have a co-existing mental health diagnosis. While we have met with the classic siloing of government funds, regulations, etc. creating a disjointed non-system for supports, the issues related to the inability of the I/DD population to access needed mental health supports and services continue to confound us. In fact, we have learned that the mental health world literally speaks a different language from the NYS Office for People With Developmental Disabilities (OPWDD) provider community: when the NYS Office of Mental Health (OMH) refers to dually diagnosed, they are talking about people with mental health and addiction service needs; and at the same time, the I/DD community uses the term dually diagnosed to refer to people with I/DD who also have a mental health (MH) diagnosis.

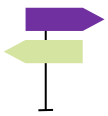
We offer this paper to suggest a path forward to align services to meet the mental health needs of the I/DD community. Here we highlight the issues as seen by our Affiliates and include recommendations that we hope will result in an improved public policy across New York State. The time is now for us to address the system shortcomings, and we believe the disability movement is truly at a crossroad when it comes to making the best policy choices for the I/DD community's mental health system needs. We look forward to assisting New York policymakers as they choose the best path forward.



AT THE CROSSROADS:

People with Intellectual and/or Developmental Disabilities (I/DD) *and* Co-existing Mental Conditions

A growing unease from providers in the **Intellectual and/or Developmental Disabilities** (I/DD) community concerning issues related to mental health services for people with co-existing mental conditions has been exacerbated with the onset of COVID-19. The umbrella organization, Cerebral Palsy Associations of New York State (CP of NYS) [i] made a leadership decision to provide its 24 statewide affiliate members and their teams an opportunity to express their views and perceived challenges related to these problems. CP of NYS hosted a series of listening sessions via Zoom with the Affiliates statewide. This paper summarizes the findings presented by these I/DD providers, related supportive research, and preliminary recommendations. It is intended to be the springboard to establishing a clear policy statement for the care of people with I/DD and co-existing mental conditions and ultimately designing an outcome-oriented plan for change.



BACKGROUND

The U.S. Surgeon General recently reported that one in five children ages three through seventeen in the U.S. have a mental, emotional, developmental, or behavior disorder.[ii] Mental disorders are defined, in the *Diagnostic and Statistical Manual of Mental Disorders*, 5th Edition (DSM-5),[iii] in sum as clinically significant cognitive, emotional regulation, or behavior disturbances that reflect dysfunction in psychological, biological, or developmental function processes.

Under the Centers for Disease Control and Prevention, federal surveillance reports have been released ranging, in two recent spans, from years 2005 to 2011 and 2013 to 2019. These documents have provided critical information to inform researchers, policy makers, providers, and funders about the prevalence of mental disorders, indicators of mental health among children and highlight primary strategies and needed services (Perou, et al., 2013; Bitsko, et al., 2022).

Perou, et al. (2013) highlighted that a total of 13 to 20 percent of children living in the U.S. experience a mental disorder in a given year and the prevalence of these conditions is increasing. Bitsko, et al. (2020) reported the prevalence of major mental disorders from the 2013-2019 surveillance data for children 3-17 years of age. Among high school students in 2019, 36.7% reported persistently feeling sad or hopeless in the past year and 18.8% had seriously considered attempting suicide (Bitsko, et al.,2022).

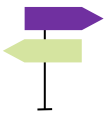
Publications on developmental and mental conditions are abundant (e.g., Ludwik, et al., 1999; (Klinger, et al., 2003; National Association of State Mental Health Program Directors [NASMHPD], 2004; 2020); Leyfer, et al., 2006; Siminoff, et al., 2008; Kerns, Kendall, Barry, et al., 2015; Chisolm, et al., 2015; Girard, 2016; Tasse, et al., 2016; Lecavalier, et al., 2018; Autism Speaks, 2017; Bradley, et al., 2019; Guerrera, et al., 2019; Hossain, et al., 2020; and Pinals,2020).

In the population of people with I/DD, researchers have identified that psychiatric conditions are common in people with autism and that there are wide ranges of prevalence reported in the literature (Lai, M.-C., et al., 2019). This is illustrated in numerous publications where it has been reported that the incidence of between 54 and 70 percent of people with autism also have one or more mental disorders (Cooper, et al., 2007; Siminoff, et al., 2008; Hofvander, et al., 2009; Romero, et al., 2016; Larson, et al., 2018; Camm-Crosbie, et al., 2019; Bradley, et al., 2019; and Rong, et al., 2021). Multiple reasons for variations in prevalence rates have been hypothesized, including differences in sample representation (e.g., population, clinical or registry based, application of DSM-5 classification for diagnostic criteria, severity of illness, age, gender, intellectual function and country of study (Romero, et al., 2016; Rong, et al., 2021). In a recent editorial, (Gotham, et al., 2020) indicate that prevalence estimates of mental health problems among autistic individuals range from "significant concern" to "epidemic concern" (p.1).

In 2019, a National Core Indictor Survey conducted in 35 states examined data from 22,513 respondents. Of this number approximately 48 percent were reported to have both an I/DD and at least one of the following mental conditions in a dually diagnosed cohort:

- Mood disorder
- Anxiety disorder
- Psychotic disorder
- Other mental disorder[iv]

Historically, the demand for treatment and services for people with I/DD and a mental condition have been found to be low. Numerous reasons for this deficiency have been recognized, including separate state and local umbrella organizations, lack of coordination and collaboration across service systems, complexity of conditions and gaps in clinical expertise (e.g., Zerbo, et al., 2015; Larsen, et. al., 2018, McDougle, 2018, in Autism Speaks; NASMHPD, 2004; 2020; Hamlin, et al., 2017; Maddox & Gaus, 2019; Maddox, Crabbe, et al., 2020).



LISTENING SESSION METHODOLOGY

CP of NYS extended invitations to their 24 Affiliates statewide to participate in a series of listening sessions. (See Appendix A: Map of CP of NYS Affiliates.) The participants included Executive Directors, Residential Directors, Day Program Directors, Clinic Directors and other professional staff.

A listening session is similar to a focus group and is a type of facilitated discussion with a group of people, aimed at collecting information about their experiences and views. Participants in these listening sessions were asked to talk about what they know and think about the care and treatment of people with I/DD and co-existing mental conditions. At times, the facilitators asked participants to answer specific questions seeking information or clarification and obtaining a deeper examination of an issue.

A total of five listening sessions were conducted via Zoom and one on-site visit. Each Zoom session was 60-90 minutes. Three large sessions included over 100 participants and two small group sessions included from four to six people each.

This paper summarizes the Affiliate responses to one key question over multiple sessions:

"What are the issues you face in caring for people with I/DD and co-existing mental conditions?"

The listening session responses are intended to provide a platform for gathering and sharing additional information, raising awareness of critical issues, and ultimately fostering change.

The findings are collapsed into four categories that naturally emerged from the sessions. Each category is followed with a brief account of what the literature tells us and followed by a series of recommendations that can be prioritized based on individual and regional specific needs

CATEGORIES:

1) **Distinguishing mental disorders and disabilities;**
2) **Diagnosis, care and treatment of co-existing mental conditions;**
3) **Crisis mental health care; and**
4) **Suicide awareness and prevention.**

DISTINGUISHING MENTAL DISORDERS AND DISABILITIES

People who have an intellectual and developmental disability and have a missed mental health diagnosis are on a path to being inappropriately treated or not getting treatment at all.

THE AFFILIATE PERSPECTIVE:

- Use of the term behavioral health does not include people with I/DD and this creates confusion.
- There's no consistent language for co-occurring condition.
- Understanding people with mental conditions by the I/DD community is inadequate.
- Understanding people with I/DD by the mental health community is inadequate.
- Assumptions and treatment decisions are made about the behavior of people with I/DD and co-existing mental conditions in a vacuum.
- Lack of vision of "whole person".
- Mental health care for people with I/DD is not equal to health care treatment (e.g., dental, nutrition, vision, and physical care) they receive.

A recent study (The ARC, 2019) included people with I/DD and co-occurring mental health issues, family members and professionals. They reported that there were ineffective communications among people, families and professionals. Young adults with mental health conditions explained that "simply being able to understand professionals and be understood by professionals is a challenge" (The ARC, 2019, p.4). Others identified a lack of appropriate resources, a lack of community awareness and a need for supports that reflect the person's religious and family beliefs. Many participants felt that they were not believed or valued in talking with professionals.

RECOMMENDATIONS:

- **Limit use of the terms "co-existing," "co-occurring," and/or "dual diagnosis" as stand alone, for example, people with I/DD and co-existing mental health condition.**

- **Develop a culturally responsive and inclusive plan for cross-education of disability and mental health providers.**

- **In seeking primary and/or psychiatric treatment in routine care, emerging crisis situations and/or actual crisis for a person with a *known* co-existing condition(s), provide written documentation to share both medical and psychiatric history, including entire diagnosis(es) and treatment trajectory of the person.**

- **Evaluate and report the effectiveness of the above recommendations.**

DIAGNOSIS, CARE, AND TREATMENT OF CO-EXISTING I/DD and MENTAL CONDITIONS

Disparities in mental health care for people with I/DD are real.

THE AFFILIATE PERSPECTIVE:

- Integrating health and mental health care has not been achieved.
- Mental health issues are not recognized and therefore go untreated.
- Practitioners only see the behaviors of a person with a developmental disability.
- Omissions were attributed to diagnostic overshadowing.
- Diagnostic overshadowing occurs in all settings but more commonly during crisis events and visits to emergency departments.
- Models of community engagement and collaboration across all state and local health care, law enforcement and legal systems are not routinely applied.
- Co-location of services facilitated access to multiple physical health and mental health care.
- People living in rural areas rely on accessing services in co-located centers.
- Need for separate and unique focus for mental health issues under the umbrella of OPWDD was identified.
- Lack of understanding and compassion for people with I/DD was expressed.
- 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.
- Polypharmacy for health and mental health conditions was seen as a problem that goes unrecognized.
- Psychiatric Services and Clinical Knowledge Enhancement System (PSYCKES)[v] is a valuable tool in the clinic to address polypharmacy.
- Long waits, more than 12 months, for staff hiring request from OPWDD added to burden of care.
- Challenges associated with recruitment and retention were identified as serious.
- Newly hired staff were too inexperienced to address mental health needs of people with I/DD.
- Critical need for educational programs about mental health, wellness and wellbeing for direct care staff.
- Concern expressed for the mental wellness of staff.

"[I] witnessed a person with I/DD being called stupid by an inpatient mental health caregiver."

Affiliate Comment

Maddox, B.B., Crabbe, S., et al., (2020) focused on identifying ways to improve community mental health care for individuals with autism and co-occurring psychiatric conditions. The title of this paper – **"I wouldn't know where to start…"** – pinpoints the problem of treating this population. Study results reported that clinicians' limited knowledge, lack of experience, poor competence and low confidence working with adults on the autism spectrum were barriers to treatment. Other findings highlighted system failures between mental health and developmental disability systems.

"Autism rarely travels alone, and detangling and treating these co-occurring [mental health] conditions as early as possible is very important to helping children and families realize a better quality of life." (Dr. Butter, in Autism Speaks 2021)

Camm-Crosbie, L., et al. (2018) focused on studying the treatment and support experience for the mental health associated challenges of individuals with Autism Spectrum Disorder (ASD). Table 1 gives a summary under the themes of no support, lack of understanding and knowledge and negative impact on wellbeing. Results point to the need to tailor psychiatric treatments. Most recently, Brede, et al. (2022) in a comprehensive systematic overview of qualitative research on the experience of adults with ASD in accessing mental health supports, highlights the fact that current mental health services do not adequately support their needs. Conclusions of this study called for larger scale studies.

Table 1. Thematic table showing the overarching theme, three themes and eight sub-themes.

Tailored support is beneficial and desirable							
'People like me don't get support'			Lack of understanding and knowledge			Well-being	
Dismissed for treatment or support because seen as 'coping'	Support geared towards children	Long waiting lists and lack of funding	Obstacles to access and receiving treatment and support	Not believed or listened to	Not suited to my needs	Negative impacts	Positive and enabling

Reprinted. Camm-Crosbie L, Bradley L, Shaw R, Baron-Cohen S, Cassidy S. 'People like me don't get support': Autistic adults' experiences of support and treatment for mental health difficulties, self-injury and suicidality. Autism. 2019 Aug;23(6):1431-1441. doi: 10.1177/1362361318816053. Epub 2018 Nov 29. PMID: 30497279; PMCID: PMC6625034.

"Our local college is doing monthly wellness classes for our staff…it's helpful."
Affiliate Comment

RECOMMENDATIONS:

- **Make mental health, wellness and wellbeing a priority in every Affiliate child and adult program/service. This includes assessment, treatment, documentation and follow-up in schools, clinics, day habilitation, supported apartments, and respite.**

- **Identify priority populations for people with I/DD who have co-existing mental conditions.**

- **Design a system for measuring and reporting the outcomes experienced by individuals who receive services in the disability delivery system.**

- **Develop a culturally sensitive cross-education plan for curriculums in schools of medicine, nursing and social work that address people with disabilities and co-existing mental conditions with FY2024 recommendations.**

- **Seek continuing education courses for licensure. Offer clinical rotations in practices that treat people with co-existing conditions (e.g., primary care, including pediatric, adolescent, young adults, adults and elder care, and in psychiatry).**

- **Create master contact list in each Affiliate region that identifies professionals who are experienced in treating people I/DD with a co-existing mental health diagnosis.**

- **Routinely screen for depression in children and adults with Autism Spectrum Disorder (ASD).**

- **Explore opportunities where tele-psychiatry (video and/or audio) is available, regardless of funding source, for potential access and/or where new developments can occur. (See CMS 2022 Physician Fee Schedule Final Rule as it applies to mental health services at home.)**

- **Request NYSTART to participate in the National Center for Start Services newly approved $4.86M in research funding to study Telemental Health Services on Mental Health Outcomes for people with I/DD.**

- **Explore educational opportunities for direct support staff to increase their understanding of mental health and wellness. Use best practice programs like Mental Health First Aid. Seek out courses at local colleges.[vi] Provide funding for staff to attend.**

- **Expand products in the CP of NYS online library. Add online courses offered by NYSTART program to all Affiliates, specifically for people with I/DD and mental health conditions.**

- **Routinely provide staff training about what to look for in a person's behavior that is different than usual, and what actions to take. Develop protocols for documentation and reporting criteria of behavioral changes.**

- **All needed training for mental health supports must be funded by the State.**

- **Expand use of PSYCKES to all community clinical settings.**

- **Adopt the use of integrated Mental Health Treatment Guidelines for Prescribers in Intellectual and Developmental Disorders.[vii]**

- **Review all products from the Centers of Excellence (2017) for current application and use.[viii]**

- **Seek continued funding for the Centers of Excellence and expand to other regions.**

- **Explore using data repositories created by Centers of Excellence across all Affiliate sites.**

- **Identify where Affiliates are currently using best practice models for the purpose of sharing experiences and replicating to new sites.**

- **Routinely measure and report person and system outcomes of best practice applications.**

CRISIS MENTAL HEALTH CARE

"A working mental health crisis system is one that provides communities with a continuum of services, including prevention, crisis response and post-crisis care."[ix]

THE AFFILIATE PERSPECTIVE:

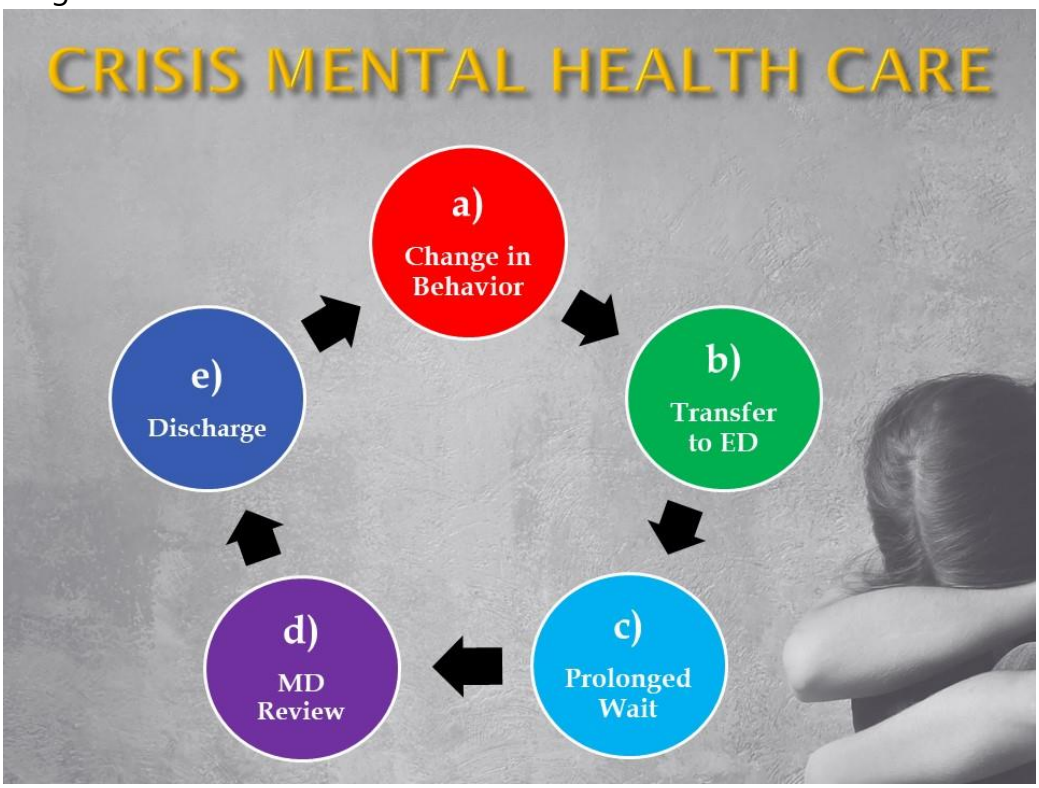
- Critical need identified for formalized staff training in crisis management (e.g., de-escalation techniques, and crisis stabilization).
- Critical need for 24/7 professional support in managing situations where a mental health crisis is escalating.
- Unsafe situations for staff and residents arise related to lack of support in crisis.
- Pandemic related decrease in staffing levels compromised safety for staff and residents.
- Crisis mental health services, including telehealth, telepsychiatry, and mobile crisis teams in most locations were limited or non-existent.
- Delays in transfer of a person in crisis to a hospital occur due to current mental hygiene law and powers of the directors of community services.
- Mental health crises are serious, frightening, and dangerous circumstances.
- A cyclic pattern, as illustrated in Diagram 1, for a person having a mental health crisis is common. It includes:
    a) change in behavior (e.g., outburst, self-injury, and/or threat to others);
    b) call for help and transfer to an emergency department (by police, ambulance, or family or friend);
    c) prolonged wait (hours, days, or more) to be seen by a physician;
    d) inadequate physician assessment (not skilled at distinguishing mental health problem in I/DD patients);
    e) pressure to discharge with medication order (most frequent treatment) to deal with presenting issue; lack of appropriate discharge planning.

  This cycle often repeats itself in the near future due to inadequate mental health assessment and treatment in the emergency department and inadequate linkage to aftercare in the community.

"The issues of MH crisis are broad and beyond the I/DD population. This is the same issue for anyone in a MH crisis these days. Children especially…"
Affiliate Comment

"Everything was calm and then all of a sudden he picked up the fire extinguisher to throw it."
Direct Support Professional [DSP] Comment

Diagram 1.



This pattern was identified in some, if not most, situations as a vicious cycle of the person again having a mental health crisis and transferred once more to an emergency department.

- Follow-up orders at discharge were not always provided.
- Admission to inpatient care occurred if the emergency provider could not discharge the person back to the community.
- Inpatient care was not always provided in a psychiatric designated hospital unit.
- Beds at Comprehensive Psychiatric Emergency Program Services (CPEPS) and/or respite locations were generally not available. Time in the emergency area was often expanded from hours and days to weeks and beyond. Shortages of available psychiatric beds delayed treatment. Children were placed on adult units in general hospitals in a holding pattern when psychiatric beds were not available. Burden on both the person and others traveling long distances to a hospital with psychiatric bed openings were identified.
- Based on the length of inpatient stay, the challenge to return the person to the same community residential setting was at times difficult or impossible.
- Respect in emergency departments not always shown.
- Episodes of persons going through crisis, experiencing increased post separation trauma.

"A person was held in the ED for one year."
Affiliate Comment

"Patient discharged from the emergency department in his underwear."
Affiliate Comment

- Affiliates in both rural and urban settings identified issues with the NYStart Crisis program that have evolved over time (e.g., hotlines down, unavailability of staff support, services lacking).
- Review progress on recommendations to NYStart leadership for FY2021/22 from The Center for Start Services.[x]
- Review OPWDD adoption and evaluation of Prescribing in Mental Health Crisis from The Center for Start Services.

"After START training need a unit on the ground to work with staff directly."

Affiliate Comment

In 2018, Dr. Luther Kalb, in an interview with Autism Speaks states that, "youth with autism spectrum disorder (ASD) exhibit high rates of psychopathology" and further indicates that "symptoms can pose a risk of injury to self or others when the child is in crisis" (p.1). He explained a mental health crisis as first "involving an acute psychiatric event (e.g., attempted suicide, elopement or wandering, self-injury and/or dangerous impulsivity that requires immediate intervention" and "second as involving a lack of resources (parent or caregiver's ability) to manage the dangerous situation".

RECOMMENDATIONS:

- **Use standardized culturally sensitive mental health crisis assessment tools to determine severity of emotional symptoms.**
- **Explore funding an advocate to be present with a person in an emergency department to assist navigating the experience and offering support to the individual and family.**
- **Explore revising current mental hygiene law, Chapter 27, Title B, Article 9.45 on emergency assessment for immediate observation, care and treatment; and powers of directors of community services to clarify the designee as a I/DD provider.**
- **Negotiate use of crisis stabilization centers for people with I/DD and co-existing mental conditions.**
- **Examine trauma care needs of Direct Support Professionals.**
- **Develop trauma culturally sensitive informed training for all professional and para-professional I/DD workers.**

- **Provide additional dedicated child and adult psychiatric inpatient beds in New York State, local (county), general and/or psychiatric hospitals in locations of greatest need.**

- **Consider specialty hospitals for patients with I/DD and co-existing mental conditions and/or dedicated units in state/county psychiatric hospitals. (Build on current models, e.g., proposed State University New York Upstate Medical University in Syracuse; Erie County Medical Center in Buffalo; and Kings County Hospital Center in Brooklyn.)**

- **Provide additional residential treatment programs (e.g., Baker Victory Services in Buffalo).**

- **Provide psychiatric inpatient and community staff training in the care and treatment of people with I/DD and co-existing mental conditions.**

- **Provide additional child and adult respite programs in locations of greatest need.**

- **Commission a mental health crisis study for people with I/DD. Results to be submitted to the Governor and legislative leaders. Study purpose is to examine the whole mental health crisis situation from beginning of crisis cycle. For example, include responder's actions, role of crisis mental health mobile teams, initial emergency department practices in assessing and treating people with I/DD and co-existing mental condition(s). Include after care when discharged to community and re-admissions periods. Include care and treatment in admission to inpatient settings, length of stay, and discharge care. Include family and caregiver perspectives.**

- **Provide opportunity for staff support and counseling in situations where an incident has occurred and a person has threatened injury to self and/or causes injury to staff and/or others.**

- **Ensure providers of I/DD services receive funding to support the additional staff training required and needs to ensure competency to prioritize mental health supports.**

SUICIDE IN PEOPLE WITH I/DD AND CO-EXISTING MENTAL CONDITIONS

"Suicide in people with I/DD happens."

THE AFFILIATE PERSPECTIVE:

- Critical need for educating all staff about suicide and suicide prevention strategies.
- Missed opportunities to identify signs of depression.
- Critical need to openly talk more about this.

"A resident attempted suicide by jumping from the second story of the building…I didn't see it coming."
Staff Comment

"Even the most skilled practitioner, family and/or friend can miss the signs…but training of what to look for is essential."
"Dr. Carpinello."

Suicide is a serious public health problem in the United States. It is a leading cause of death and claimed the lives of nearly 46,000 people in 2020. Suicide was the second leading cause of death among individuals between the ages of 10 and 14, and individuals between the ages of 25-34.[xi]

The incidence of suicide in people with I/DD has recently been identified in literature (e.g., Kalb, et al., 2017; Cassidy, Bradley, Bowen, et al., 2018; Camm-Crosbie, et al., 2019; Kirby, et al., 2019; Kirby, 2019, in Autism Speaks; and Mann, et al., 2021). Dow, et al. (2019) examined the occurrence of depression, anxiety and suicidality in adults with Autism Spectrum Disorder (ASD), the relationships between social difficulties and mental health, and application of the Interpersonal Theory of Suicide. Results reported a lifetime history of anxiety (55 percent), depression (55 percent), suicide attempts (19 percent) and recent suicidal ideation (12 percent). Here social difficulty was associated with higher psychiatric concerns. These researchers point to the need for widespread screening and intervention services for people with ASD and co-existing mental conditions.

"People with I/DD present a similar suicide risk to the general population, but it remains poorly understood."
(Dr. Bardon, 2021)

McDougal (2018, in Autism Speaks) addresses the absence of addressing suicidal tendencies when diagnosing depression and treatment of depression. Kirby, et al. (2019) highlighted the findings that females with autism were three times more likely to attempt suicide than those without a diagnosis of autism.

Cassidy, F., Bradley, L. and Shaw, R., et al. (2018) go further to explore suicide in autistic adults by asserting that the rates are high in autism spectrum conditions but ask why is that so? (p.1) Their research looks to identify risk markers for suicidality. One result points to unique factors that increase risk of suicidality, including camouflaging and having unmet support needs.

Bardon (2022) in a recent webinar shared a research program aimed to improve the understanding, assessment and prevention of suicidal behavior in people with I/DD. Suicide prevention experts, I/DD researchers and clinicians developed a dynamic model of suicide risk, a series of tools to support suicide prevention (assessment and intervention) and a strategy to support the use of these tools in clinical settings.

RECOMMENDATIONS:

- **Adopt the New York zero-suicide in written OPWDD policy.**
- **Review factors related to suicide deaths in people with I/DD.**
- **Consult with experts at New York State Suicide Prevention Center for information that can be tailored or adopted for people in the I/DD community.[xii]**
- **Speak up about suicide prevention in people with I/DD and co-existing mental conditions, their family and community members.**
- **Educate (in-person or online) direct support staff about suicide screening, early intervention, and prevention. Use best practice sponsored programs (e.g., American Foundation For Suicide Prevention; Suicide Prevention Awareness Resource Center; and Applied Suicide Intervention Skilled Training [ASIST]).[xiii & xiv]**
- **Perform early culturally sensitive risk assessments in multiple settings to evaluate the effectiveness of treatments in children and adults.**
- **Negotiate a place at table with the Office of Mental Health (OMH) and Office of Addiction Services and Supports (OASAS) for 988 lines.**
- **Review training materials for 988 lines for content related to "talking" to people with ASD and co-existing mental conditions.**

- **Provide opportunity for staff support and counseling in situations where a person threatens suicide, attempts suicide and/or completes suicide.**

- **Provide opportunity for family counseling in situations where a family member threatens suicide, attempts suicide and/or completes suicide.**

- **Plan summit with key state and local leaders, providers and other key stakeholders to develop an action plan for change.**

COMMENTARY

CP of NYS Affiliates have provided us with information that singly or collectively could "delay" or "prevent" a person with co-existing Intellectual and/or Developmental Disabilities and Mental Health Condition from being adequately treated 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, lack of education for primary care doctors and psychiatrists, and the cyclic nature of emergency care.

The burden of the failure to collectively go forward across multiple state and local agencies will fall to the leaders (officials) and ultimately on the shoulders of the people, their families and the staff who care for them.

To be sure, most of this information, although alarming, is *not* new. That is the unnerving part. It has been reported in multiple federal and state venues. In fact, in New York, many of these issues were outlined and subsequent recommendations drafted some five years ago in the comprehensive Centers of Excellence Report (2017). Unfortunately, due to lack of funding, there was no action taken on these recommendations. Today, their voices have real meaning because of a history of repetitive failures in the care of people with I/DD and co-existing mental conditions.

These honest accounts from the field leave me confused; where is the evidence of these claims about what "is working" or "not working" in this public health system? *Where is the evidence?* What data is routinely collected and how is it reviewed and reported to be used for improving care? Are there any performance management systems in place?

As someone who has strongly advocated to "pay for what works" in health care we have an obligation to our funders and other stakeholders to collect and provide individual, family and system outcomes data. This could be distributed in many formats from reports, dashboards to on-line report cards and public forums. Our legislative leaders need to demand this. They need this information.

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. This is a unique opportunity for the newly appointed OPWDD Commissioner Kerri Neifeld, who has signaled her commitment to listening to the disability community and other state partners to foster real change.

ACKNOWLEDGEMENTS

Our affiliates work on the front lines to support people with I/DD, and we thank all our CP affiliate participants for their contribution to this paper and to the time devoted to talking about some difficult and complex issues.

Many thanks to Cheryl Bradway for her creative design and attention to detail in pulling this publication together and keeping us on track throughout the process. As always, her work is first-rate and her contribution invaluable to our effort.

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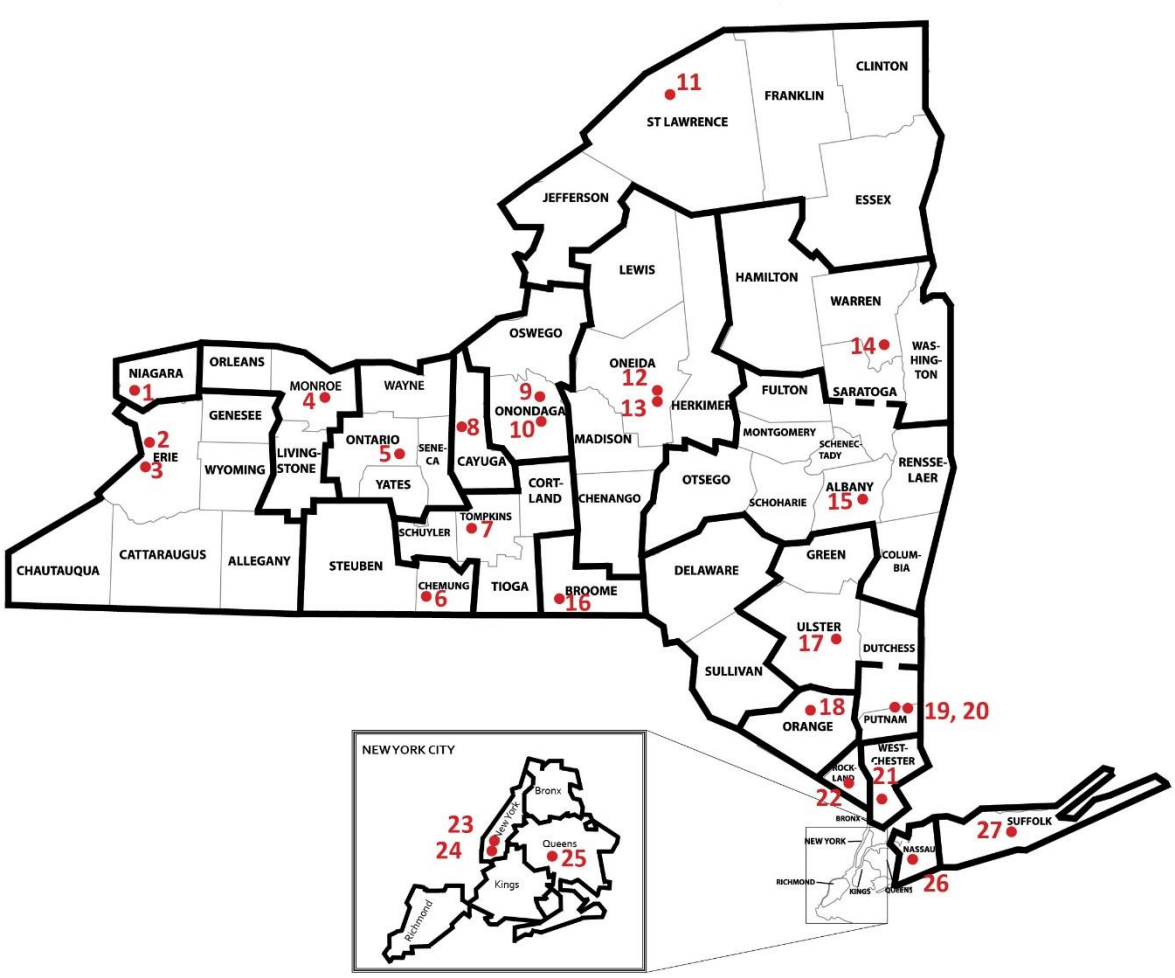
APPENDIX A

CP of NYS Affiliates



1. Empower
2. Aspire
3. Evergreen Health System
4. CP Rochester
5. Happiness House
6. Able2
7. Racker
8. E. John Gavras Center
9. Advocates, Inc.
10. AccessCNY
11. Cerebral Palsy Association of the North Country
12. Upstate Cerebral Palsy
13. Kelberman Center
14. Prospect Center Division (CFDS)
15. Center for Disability Services
16. HCA - Helping Celebrate Abilities
17. Wraparound Services of the Hudson Valley
18. Inspire
19. Hudson Valley Cerebral Palsy Association
20. Constructive Partnerships Unlimited - Hudson Valley Division
21. Cerebral Palsy of Westchester
22. Jawonio
23. Constructive Partnerships Unlimited
24. ADAPT Community Network
25. Queens Centers for Progress
26. Cerebral Palsy of Long Island
27. UCP of Long Island

SOURCES

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[xiii] American Foundation for Suicide Prevention. https://www.afsp.org

[xiv] Suicide Prevention Resource Center. https://www.sprc.org

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