



Cerebral Palsy Associations
of New York State

Real people. Realizing potential.

Prioritizing Health Equity for People with I/DD in NYS

The Smart Thing *and* The Right Thing To Do

April 2022

CP of NYS
POLICY RECOMMENDATIONS

www.cpstate.org



Executive Summary



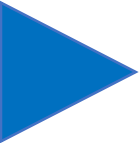
Universally, people living with disabilities are underserved. “When people with disabilities access health care, they often experience stigma and discrimination, and receive poor quality service.” People with I/DD have health needs that are the same as for non-disabled people: immunizations, annual physicals, cancer screenings, dental cleanings, etc. Evidence suggests that people with disabilities face obstacles in accessing the health and rehabilitation services they need in many settings.

One result of this inequity is “increasing numbers of persons with multiple, complex and often preventable, chronic conditions and a health care system insufficiently prepared educationally, structurally and economically to recognize and address those needs.”

We believe that health equity for people with I/DD should be a paramount policy goal in NYS. At the same time that people with I/DD are being denied equitable access to care, the cost of care for their complex needs far exceeds any investment in preventive, primary, or specialty care. We offer this overview of the issue with our initial recommendations in the hope that policy makers will come to realize that investing in ensuring health equity for people with I/DD in New York State is not only the right thing to do, but it is also the smart thing to do from a public policy perspective.

Simply put, people with complex needs, different needs, and/or higher needs than the typical Medicaid population require more time, expertise, follow up and care integration. These essential factors are not accounted for in a meaningful way under current Medicaid payment methodologies.

A key goal of this paper aligns with the research that has demonstrated “empirically that providing more equity-oriented health care (EOHC) predicts better patient health outcomes over time. At a policy level, . . . research supports investments in equity-focused organizational and provider-level processes in primary health care as a means of improving patients’ health, particularly for those living in marginalizing conditions.”



We need to pull the pieces of the fractured disability health community together and provide a centralized, adequately sourced, dedicated approach and resources to develop data and research necessary to identify best practices and protocols in providing support for high needs, complex individuals that will ultimately lead to cost-efficient, quality outcomes.

Key challenges to health equity for people with I/DD:

Clinician Training/Readiness

The shortage of trained clinicians has reduced access to care for a highly vulnerable population. Among the areas of concern, that are prioritized by the CP Medical Directors, is the need for the recognition of specialty training in complex needs (particularly with the I/DD population), obtaining a federal designation of the I/DD population as a medically underserved population (MUP), requiring increased clinician training in working with the I/DD community.

Medical Complexity/Centers of Excellence

We have found that medical complexity is just that. It takes trained clinicians and a broad approach to diagnoses and care that is often missing in a fragmented system. In addition to the need for I/DD population trained clinicians, there should be an approach as identified in the CP of NYS-led Centers of Excellence to address the treatment and support of people with complex people with needs.

Telehealth

It is critical that we move quickly to ensure disability policy includes regulatory, reimbursement, and policy alignment to permit expansion of innovations in telehealth for those with intellectual and developmental disabilities and traumatic brain injuries. As high users of health care, with complex conditions, the I/DD population have already benefited through this technology which can improve health care outcomes and decrease costs for this population.

The CP of NYS Telemedicine Triage project, which was up and running in March 2020 — the start of COVID — includes 8,315 participants with I/DD living in over 1,000 certified residences across the State. These certified residences include CP Affiliates and other organizations' residential services as well. Initial review of this project/model shows it has generated statewide Medicaid system savings of minimally \$50 million in its first 18 months.

Mental Health

More than a decade of research has demonstrated that co-existing mental disorders in people with I/DD may be more prevalent than known or generally understood. We are in the process of developing recommendations reflecting the outcomes of a series of listening sessions. A report, *At The Crossroads: People with I/DD and Co-existing Mental Disorders*, will be released separately in 2022.

COVID and I/DD Providers' Place in The Health System

Policymakers need to understand the role the I/DD provider community plays as part of the health system. The clinical supports provided in a residential, day program or the I/DD focused clinic have profound impacts on the way people with I/DD use urgent, ER, long-term and acute care services in traditional models. We believe the opportunity for payment model exploration and improved integration with the health system must be seized upon immediately to correct this.

Community Health Outreach Project (CHOP)

Gaps in the health care system for the typical population are even more profound for people with higher needs, and particularly for those with I/DD. Due to utilization management controls, which are geared to the typical low needs population and don't contemplate people with high need health requirements, approvals for treatments/items fail to incorporate an appreciation of the fact that a particular high-cost service/item is not only justifiable but is cost efficient for those with I/DD.

A Mother Cabrini Health Foundation grant allowed CP of NYS to create the Community Health Outreach Project (CHOP) which is structured to ensure that social determinants of health are considered, when other funding is not available, as we try to meet the health needs of people with I/DD.



While it's terrific that we have a temporary funding source to meet these health needs, the broader question remains: why is the funding for this group falling short of meeting their health care needs? We assert that the fractured delivery of care, and higher system costs could be avoided with a more centralized approach to disability health services.

Conclusion

We are asking that NYS considers moving a high need — high cost — complex population that does not fit into our current funding and regulatory constructs to a systemic approach of supports and services for people with I/DD. Again, this is not only the right thing to do to improve the quality of life for people with I/DD, it is the smart thing

to do because this streamlining and barrier removal will save or prevent costs.

We know that we need partners to get this done, and CP of NYS is here and ready to begin work on any and all these proposals.

NOTE: The specific recommendations are found throughout the document and [HERE](#).

Prioritizing Health Equity for People with I/DD in NYS

INTRODUCTION

Universally, people living with disabilities are underserved. “When people with disabilities access health care, they often experience stigma and discrimination, and receive poor quality service.”¹ Healthy People 2020, using the WHO model of social determinants of health, recognizes that what defines individuals with disabilities, their abilities, and their health outcomes more often depends on their community, including social and environmental circumstances.

People with disabilities not only require support to attain improvements in the social determinants of health, they also are significantly underserved: research shows that people with physical disabilities/cognitive limitations, “as a group, experience health disparities in routine public health arenas such as health behaviors, clinical preventive services, and chronic conditions. Compared with individuals without disabilities, individuals with disabilities are:

- 1. Less likely to receive recommended preventive health care services, such as routine teeth cleanings and cancer screenings**
- 2. At a high risk for poor health outcomes such as obesity, hypertension, falls-related injuries, and mood disorders such as depression”²**

Throughout this document we use the term “people with intellectual and developmental disabilities (I/DD)” and for our purposes it includes people with autism spectrum disorders, cerebral palsy, Down syndrome, traumatic brain injuries (many are veterans), fragile X, fetal alcohol syndrome and more than 1,000 other diagnoses. In addition, there is a significant portion of the I/DD population with co-existing mental health disorders (e.g., attention deficit and hyperactivity disorder, anxiety disorder, depression, bipolar disorder, and schizophrenia — more than 50% of people with Autism have been found to have co-existing mental health disorders). Disability crosses all age groups, race, and other demographics or political party.

Traumatic Brain Injury (TBI) patients, often veterans, require many of the same care considerations as the I/DD population and many of our clinics include those patients in their clinic rosters. Any policy change considerations should include the TBI population as well.

Barriers to Health for People with I/DD

The World Health Organization's (WHO's) 2021 report³ noted that people with disabilities encounter a range of barriers when they attempt to access health care including:

1) Attitudinal Barriers

- a. People with disabilities commonly report experiences of prejudice, stigma and discrimination by health service providers and other staff at health facilities.
- b. Many service providers have limited knowledge and understanding of the rights of people with disability and their health needs and have inadequate training and professional development about disability.
- c. Many health services do not have policies in place to accommodate the needs of people with disability. Such policies could include allowing longer and flexible appointment times, providing outreach services and reducing costs for people with disability.
- d. Women with disability face particular barriers to sexual and reproductive health services and information. Health workers often make the inaccurate assumption that women with disability are asexual or are unfit to be mothers.
- e. People with disability are rarely asked for their opinion or involved in decision-making about the provision of health services to people with disability.

2) Physical Barriers

- a. Health services and activities are often located far away from where most people live or in an area not serviced by accessible transport options.
- b. Stairs at the entrance to buildings or services and activities located on floors which do not have elevator access are inaccessible.
- c. Inaccessible toilets, passages, doorways and rooms that do not accommodate wheelchair users, or are difficult to navigate for people with mobility impairments, are common.
- d. Fixed-height furniture, including examination beds and chairs, can be difficult for people with disabilities to use.
- e. Health facilities and other venues for activities are often poorly lit, do not have clear signage, or are laid out in a confusing way that makes it hard for people to find their way around.

3) Communication Barriers

- a. A key barrier to health services for people who have a hearing impairment is the limited availability of written material or sign language interpreters at health services.
- b. Health information or prescriptions may not be provided in accessible formats, including Braille or large print, which presents a barrier for people with vision impairment.
- c. Health information may be presented in complicated ways or use a lot of jargon. Making health information available in easy-to-follow formats — including plain language and pictures or other visual cues — can make it easier for people with cognitive impairments to follow.

4) Financial Barriers

- a. Over half of all people with disabilities in low-income areas cannot afford proper health care.
- b. Many people with disabilities also report being unable to afford the costs associated with travelling to a health service and paying for medicine, let alone the cost of paying to see a health service provider.

People with I/DD have health needs that are the same as for non-disabled people: immunizations, annual physicals, cancer screenings, dental cleanings, etc. Evidence suggests that people with disabilities face obstacles in accessing the health and rehabilitation services they need in many settings.

One result of this inequity is “increasing numbers of persons with multiple, complex and often preventable, chronic conditions and a health care system insufficiently prepared educationally, structurally and economically to recognize and address those needs.”⁴

Additional facts about disability health:

19 percent of people with disabilities reported that they did not receive medical care needed in the previous year, compared to 6% of nondisabled persons.

Those who did not receive treatment attributed the failure to reasons that included a lack of insurance coverage (35%), high costs (31%), problems getting to provider offices or clinics and inadequate transportation (11%), and difficulties or disagreements with doctors (8%).

Among women with physical disabilities, nearly 1/3 report being denied services at a doctor’s office solely because of their disabilities, and 56% of women with disabilities who have given birth in hospitals reported that the hospital had failed to prepare for needed disability-specific accommodations.

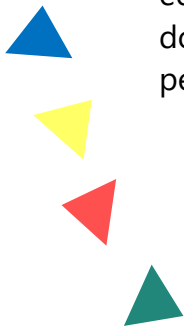
Children with DD were more likely than typically developing children to have a fair or poor health status (27.7% vs. 1.1%), have two or more overnight hospitalizations (8.5% vs. 0.7%;), experience delayed treatment (10.1% vs. 2.4%;), and have one or more unmet healthcare needs (19.6% vs. 5.7%).⁵

The need for health care is great and we are in a time of unprecedented workforce shortages, particularly for direct care workers: “New York . . . will feel the effects of the [lower wage] labor shortage most acutely, [with the State] projected to fall short by 500,000 [of these health workers] as soon as 2026. . . . To replace that amount of labor in that amount of time, employers

will need varied and creative strategies.”⁶ On top of that, a significant component of the care currently provided to people with disabilities is performed by parents and family members, many of them aging parents with decreasing ability to maintain that level of care. Both the shortage of direct care workers and the disability community’s dependence on family supports for care are problematic given the demographics of New York’s population and workforce projections.

These factors together indicate a need for public health interventions that address the unique characteristics of people with disabilities, many of whom are at risk for high cost, debilitating conditions that may not have as severe an effect on other population segments. A key goal of this paper aligns with the research that has demonstrated “empirically that providing more equity-oriented health care (EOHC) predicts better patient health outcomes over time. At a policy level, . . . research supports investments in equity-focused organizational and provider-level processes in primary health care as a means of improving patients’ health, particularly for those living in marginalizing conditions.”⁷

We believe the goal of health equity for people with I/DD should be a paramount policy goal in NYS. At the same time people with I/DD are being denied equitable access to care, the costs of care for their complex needs far exceed any investment in their preventive, primary, or specialty care. We offer this overview of the issue with our initial recommendations in hopes that policy makers will come to realize that investing in ensuring health equity for people with I/DD in New York State is not only the right thing to do, but it is also the smart thing to do from a fiscal and public policy perspective.






CP – A HISTORY OF HEALTH SERVICES

Much of what has informed the CP of NYS position on the challenges of ensuring health equity for New Yorkers with I/DD is based on our Affiliates' and other colleague agencies' more than 75 years of history finding or providing health and other services for people with I/DD. In 1946, CP of NYS was founded by parents of children with cerebral palsy looking to find services for their children. Today we are a broad-based, multi-service organization with 24 Affiliates across New York providing supports/services for over 100,000 people with I/DD and their families. CP and our Affiliates have come together to carry out our joint purposes of advocating with and for people with I/DD, including cerebral palsy, and other significant disabilities. Our goals and values drive our decisions to develop programs that improve their health and quality of life.

In the course of those almost eight decades of providing services, CP Affiliates have developed services licensed under the NYS Department of Health (DOH), the Office for People with Developmental Disabilities (OPWDD), the NYS Education Department (SED), the Office of Mental Health (OMH), the Office of Children and Family Services (OCFS), and others. Our provider agencies — many years before exploring the social determinants of health became popular in the health provider community — have always focused on the whole person's needs for health and well-being, including housing, employment, social supports, as well as access to traditional health care services. For more than 35 years, we have operated an array of Article 28 health clinics with a focus on supporting people with I/DD, Article 16 clinics under OPWDD, and even Article 31 clinics under OMH. We began and continue to operate these clinics — many of our Article 28 clinics have transitioned to federally qualified health center (FQHC) status — despite losing an average of 20% on operations for many years. The mission of the CP Affiliates and other I/DD focused clinic operators has driven boards to find other ways to support this under-funded service — our Boards and administrators know that, if these specialty clinics were to close down, there are no other options for health care for our patients.



Patients supported by our Affiliates and other agencies often have complex needs, with multiple diagnoses and typically some limits on their ability to communicate in a manner that most clinicians can understand. This essentially leaves them stranded without community provider options. What we see happening when our services are no longer available has been anything from an immediate rise in ER and other visits for ambulatory care sensitive conditions to a longer-term impact when untreated patients show up in hospital ERs for easily treatable conditions or require hospital OR time for dental procedures that could have been managed through regular dental care. The long-term impact of this practice is not person oriented, safe or effective.

And why do our clinics and supports fail at a minimum to break even on operations? Simply put, people with complex needs, different needs, and/or higher needs than the typical Medicaid population require more time, expertise, follow up and care integration. These essential factors are not accounted for in a meaningful way under Medicaid payment methodologies. To ensure access to care for people with I/DD, we have created programs with high cost people clustered in a way that the State's Medicaid payment program, which incorporates the full population bell curve or case mix of patient severity, cannot accommodate or recognize. Rather than recognize the work being done in the specialty I/DD clinics with adequate reimbursement, the State continues to hold our Medicaid payments and utilization management controls to those expected for a typical population.*

A few examples of the problems our clinics face include those providing oral health services to people with I/DD who cannot bear a whole mouth cleaning twice a year as is the care standard for most patients. Many of our patients require their cleanings to be done by quadrant — their cognitive, behavioral, and/or physical complexity limit the amount of time they can sit for a cleaning — but we regularly have to return to our billing auditors to explain why more than the standard cleaning level is necessary. Similarly, people with I/DD do not fall into the general health care curative mindset — most of the conditions associated with various diagnoses include a treatment goal of “prevention of regression” or simply making sure their flexibility, strength, etc. don't get worse. There are many conditions — unlike the typical population's broken leg treatment and follow up therapy — that aren't going to be “cured.” Additionally, when someone with complex needs

**EDITOR'S NOTE: When DOH first calculated APG's there was an acknowledgement of the complexity of the “CP/DD grouping” requiring higher rates, with an intent to analyze whether that increased payment was satisfactory — that examination never took place.*

Affiliates' Services and Funding

The majority of services provided by CP Affiliates include the following list of programs, among others, and the certifying agency. OPWDD, DOH, and OMH services are largely Medicaid funded programs and are paid at state set fees/rates. SED programs, also government funded, are state set tuition based payments for special education.

OPWDD Services (Office for People with Developmental Disabilities)

- ❖ Certified Residential Programs
 - Individual Residential Alternative (IRA)
 - Intermediate Care Facility (ICF)
- ❖ Day Hab Programs
 - Day Habilitation
 - Day Treatment
- ❖ Community Habilitation
- ❖ Article 16 Clinics
- ❖ Supported Employment
- ❖ Self-Direction

Note: Statewide, residential and day program funding accounts for almost 90% of OPWDD spending.

SED (State Education Department)

- ❖ Preschool – 4410
- ❖ School Age – 853
- ❖ ACCES-VR

DOH (Department of Health)

- ❖ Early Intervention
- ❖ Consumer Directed Personal Assistance Program (CDPAP)
- ❖ Article 28 Clinics / Federally Qualified Health Centers (FQHC)
- ❖ Licensed Home Care Services Agencies (LHCSA)
- ❖ TBI Waiver

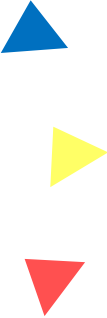
OMH (Office of Mental Health)

- ❖ Article 31 Clinics

does have an injury/health condition, they often require additional supports and/or more time. Yet we don't have a payment model that allows for this reality in a practical or fiscally supportive way.

Even though our clinics have been financial losers — disability clinics lose on average 20% on operations annually — the Boards of CP Affiliates and other disability agencies providing clinical care have prioritized ensuring

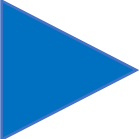
access to care and have had to subsidize the government funding with fundraising and other revenue sources. The predominance of Medicaid as a payor, limits options that are available to hospitals and other health service providers who have a payor mix that might help correct for such significant Medicaid under-payment for these critical services. Unfortunately, as funding for disability providers has grown more and more scarce, there has been renewed Board evaluation on discontinuing this essential service in many agencies, thereby further threatening people with I/DD's access to needed health care.



Why policy makers need to take note of the fragmentation and deterioration of an already tenuous system is that people with I/DD include more than 300,000 New Yorkers. Now, more than ever, the provider network has been strained to its limits with more than a decade of underfunding on top of a "system" that does not recognize the justified additional expenses related to supporting the population's needs. This significant segment of the population includes a small percent of the total population whose needs make up a significant portion of the State's spending on healthcare, which quickly spirals upward, when access to quality care is unavailable for this group's care.

The CP Affiliates' history of providing clinic and other services tells us that we do not have a unified system in New York to treat and support this high needs, high cost segment of the Medicaid population. What health "system" we have is under tremendous stress from both a workforce crisis and financial shortsightedness. Ensuring health equity is needed to: provide this population access to health care; provide clinician training in disability services, including intellectual/developmental disability and TBI; and leverage technology such as the increased use of telehealth to improve health metrics. We need to pull the pieces of the fractured disability health community together and provide a centralized, adequately sourced, dedicated approach and resources to develop data and research necessary to identify best practices and protocols in providing support for high needs, complex individuals that will ultimately lead to cost-efficient, quality outcomes.

To that end, CP of NYS has worked with its Affiliates and other providers to combat different components of the fragmented system over the years, but to date we have been unable to persuade policymakers that their support of these activities will offer a broader application to benefit the entirety of the disability community.



Key challenges to health equity for people with I/DD include:

Clinician Training/Readiness

CP of NYS Affiliates, as noted previously, have a strong history of developing clinics to support people with I/DD, and our Association has in place clinical committees for those who operate clinics and a Medical Director's Council with broader participation to include expertise outside the "CP family." We have worked with other associations on critical health issues and identified needs and priority advocacy issues for improved health access for people with I/DD. Underlying many of the reasons our clinics were needed in the first place is the lack of access from a physical plant perspective, but also simply in the clinician supply in supporting people with different needs. We have developed clinical support models that specialize in treating people with I/DD, whether they have communication, locomotion, behavioral, or other challenges. Those accommodations often require additional time and training to provide quality care. To that end, even when a patient with I/DD is able to see a clinician not familiar with supporting the I/DD population, the untrained physician often becomes confused by the presentation of the patient and make incorrect diagnoses. This leads to diagnostic overshadowing, which assumes everything being observed is related to the disability and can lead to unnecessary testing, utilization, prescriptions, and sometimes worse, e.g., a patient sent to hospice for a simple UTI. Similarly, people with I/DD are 25% more likely to get a prescription, 300% more likely to continue a prescription, and 46% of psychotropic drugs and 13% of seizure drugs have no corresponding diagnosis.⁸ Psychotropics can cause reflux, dysphagia — which increases risk for pneumonia/pneumonitis and choking — constipation, osteoporosis, weight gain, diabetes, cavities, and more, which lead to more medications and complications.

The shortage of trained clinicians has reduced access to care for a highly vulnerable population. CP of NYS received funding from the Mother Cabrini Health Foundation to develop general clinician training/introduction to the I/DD population as a good first step in improving access by increasing the pool of clinicians able to provide quality, appropriate diagnoses and treatment (Grant Steering Committee members). For the first time in human history, there are more adults with I/DD than children; yet medical/clinician education has not kept up with the demographic shift. The average physician gets 11.4 minutes of exposure to this population in four years of training.

Thanks to this project we will be reaching at least 1,000 clinicians by the end of this year through online learning, and we hope to reach an even broader audience through our partnership with Positive Exposure which resulted in the series of videos that can be found [HERE](#).

Since 2018, the CP of NYS Medical Directors Council has held a conference on Multi-Disciplinary Clinical Care for Patients with Intellectual and Developmental Disabilities. The conference is the only interprofessional annual I/DD focused clinical conference of its kind in NYS. The conference is designed to increase clinical expertise in treating people with I/DD for various clinician types. The Medical Directors of CP of NYS understand that there is a lack of expertise in treating people with I/DD and the need for this type of training. See 2021 Clinical Conference Brochure [HERE](#).

Among the areas of concern prioritized by the CP Medical Directors is the need for recognition of specialty training in complex needs (particularly with the I/DD population), obtaining a federal designation of the I/DD population as medically underserved population (MUP), and requiring increased training in clinician training programs on working with the I/DD community.

RECOMMENDATIONS:

- **Clinicians must receive incentives to retire their educational debt for working in the disability field with individuals with I/DD.**
- **Development of Acute Care Clinician Training Requirements — Hospitals should not be allowed to medicate and release patients with behavioral health needs because there is no “system” to support their needs. A better understanding of the I/DD population, training, and care protocols are required.**
- **Clinicians training in complex care and those receiving specialty I/DD training should be provided access to federal and state education loan forgiveness programs.**
- **To ensure that complex needs are supported prior to issuance of any new health policies and regulations, DOH and OPWDD should access CP of NYS Medical Directors' Council and related I/DD health issue expertise in the review and development of health policy.**

- **To ensure health equity discussions include the I/DD community, CP and the I/DD field's clinical expertise should be incorporated as part of the regional 1115 Waiver discussions.**
 - **To ensure competency with providing disability support and care, first responders, emergency technicians, social services/child protective personnel, and family training should be expanded to include disability competencies.**
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Medical Complexity/Centers of Excellence

Under a Balancing Incentive Program (BIP) grant, CP of NYS led a project to incorporate the three largest providers of children's residential programs (CRPs) in New York State to identify best practices in supporting complex children's health needs, transitioning school age children to adult living, identifying needed data to support clinical decision making and identifying effective/cost efficient care. The project developed the Centers of Excellence (COE) in the Care and Support of Children with Autism Spectrum Disorders and Other Complex Needs. The group met for over two years and created an outline for a useful data repository, developed and began testing/using clinical screening tools, held symposiums for clinicians on pharmacology, trauma-informed care, etc., and offered the State a path forward for stemming the tide of students going out of state for care because of New York's under-funded children's residential program's inability to provide the needed supports for those children. The models developed in this project addressed complexity and included practical paths forward for policy makers, while most critically offering treatments and supports that would immediately improve the quality of life and care for those in the program. Cost efficiencies and improved quality of care were both present. Unfortunately, funding in New York is considered in silos, so while an increased expense in one fund would save funding in multiple silos across the State budget, the entirety of this project's impact on cost savings and future cost avoidance was not appreciated or supported. An enormous opportunity has been missed, and CP of NYS will continue to advocate with hope that the new administration will take a broader view of this project's impact and potential.



One of the components of care that this project emphasizes beyond the transition from child to adult is that the current system does not adequately support typical life transitions for the disability community.

While typical transitions are part of their lives, people with I/DD are also more likely to have significant changes in health status at times that don't fit the typical lifespan (e.g., early onset dementia in people with Down syndrome, diagnosis-specific progression in the thirties or forties, etc.) of those planned in the actuarial calculations of spending models. New York's policies must embrace the significant opportunity that streamlining transitions throughout life will have on the efficient use of resources across multiple funding streams. Medicaid, Medicare, education, housing and employment policies must align to ensure that our most vulnerable and often most complex members of our community are able to smoothly make life's transitions (from infancy to school, school to adulthood, employment to retirement, and finally to death with dignity) in a manner that has been planned for and resourced rather than made during crisis and confusion, which typically involve higher costs due to inefficient access to supports, and increased anxiety.

Medical complexity is just that. It takes trained clinicians and a broad approach to diagnoses and care that is often missing in a fragmented system. In addition to the need for trained clinicians for the I/DD population, there needs to be an approach as identified in the COE to address the treatment and support of complex people.

The COE project's summary and findings can be found [HERE](#).

RECOMMENDATIONS:

- **Fund the Centers of Excellence in the Care and Support of Children with Autism Spectrum Disorders and Other Complex Needs or a larger focused model on complexity. Understanding complexity will help drive the development of protocols that will both improve care and reduce or prevent additional costs. Ensure that the funding will expand the resources and required training to other agencies.**
- **Implement the recommendations of the CP of NYS data repository to ensure access to information across complex populations. NYS must dedicate Medicaid/DOH program staff to centralize the clinical analysis and evaluation of the clinical supports/interventions in conjunction with the disability clinicians who understand the population.**

- **Align data from the Centers of Excellence/COE, CP of NYS telehealth project, and other evolving research for the development of disability care research priorities in disability care.**
 - **Expand the use and support of the clinical screening tools developed under the COE and fund training and expanded clinical resources to implement the tools statewide.**
 - **Regularly convene the COE experts with cross-sector State agencies (DOH, OPWDD, OMH, SED, OCFS) and other providers to review the progress being made and work being done to ensure that the sharing of the advancements identified are incorporated in health practice across the State.**
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Telehealth

There are many pilots underway across the State and country to incorporate the use of telehealth/telemedicine in the care delivery system. CP of NYS believes it is critical that we move quickly to ensure disability policy includes regulatory, reimbursement, and policy alignment to permit expansion of innovations in telehealth for those with intellectual and developmental disabilities and traumatic brain injuries. As high users of health care, with complex conditions, the I/DD population have already benefited through this technology which can improve health care outcomes and decrease costs for this population.

CP of NYS and our Affiliates were early adopters of a telemedicine triage model under the State's DSRIP funding, specifically in the Staten Island PPS' efforts with CP of NYS in our residential programs. That model became the basis for a broader project which CP of NYS was able to expand to the entire State through a NYS DOH Health Care Infrastructure grant. Through this experience and initial outcomes, we believe it is clear that we must initiate policies and payment structures to support expanded use of telehealth for emergency medicine triage to avoid ER over-utilization, specialty care consults and specialty care visits, and primary care and specialty care follow up visits. Moreover, the use of telehealth for improving access to specialty

care, reducing transportation for follow-up visits, and general health screening to reduce the physical toll on people with I/DD, that in-person visits often present, must be part of that transition and a larger telehealth/telesupport model.

CP of NYS has recently submitted an application in the next round of infrastructure funding for a new Telemedicine Triage Extension & Expansion project that would build upon and extend the current project's success. The current project, which was up and running in March 2020 — the start of COVID — includes 8,315 participants with I/DD living in over 1,000 certified residences across the State, including not only CP Affiliates, but other organizations' residential services as well. In the first phase we identified a need for improving access to psychiatric/behavioral health services. We hope this application will be funded to pilot the effectiveness of the tele-psychiatry overlay on the telehealth triage model for 1,690 participants statewide. A summary of findings on savings can be found [HERE](#).

The intellectual and developmental disability (I/DD) community includes those with neurodevelopmental disorders (ND):

- ❖ biological conditions that disrupt the development of the brain at some point between conception and early adulthood.
- ❖ may be genetic disorders (e.g., trisomy 21, fragile X syndrome) or acquired disorders (e.g., hypoxia at birth, lead toxicity).
- ❖ As a whole, the I/DD population costs 3.6 times what the non-disabled population costs for health/Medicaid spending.⁹

The Telemed Triage service is a 24/7 Tele-Urgent Care that is staffed by ER/acute care doctors with specialized training in the medical and social challenges of people with I/DD. Services are available immediately via telemedicine technology at all times to address acute issues or any gap in care. The ER/acute care doctor evaluates and determines a course in treatment; rather than nurses or other staff sending people out of homes to the ER, urgent care or other service, the ER doctors evaluate and make the call on the appropriate action needed.

Our initial analysis of the CP of NYS's current telehealth triage model shows the use of the model has generated statewide system savings of minimally \$50 million in


its first 18 months. At the same time that CP of NYS moves forward with its telehealth work, the data from CP of NYS sponsored I/DD Accountable Care Organization/Medicare Shared Savings Program (ACO) (the first in the country), Alliance for Integrated Care of New York (AICNY), reinforces the need for telehealth supports/triage:

- AICNY data indicates that its I/DD beneficiaries experience a very high utilization of the ER when compared nationally to other MSSP ACO beneficiaries.
- Additionally, the AICNY data indicates that ER visits result in inpatient stays up to 70% of the time that averages 3 days.
- At least 50% of AICNY's I/DD beneficiaries have at least one ER visit each year, and 25% averaged 3.57 visits per year.
- The top 10% had an average of 7.22 ER visits per year.
- Extrapolating these prevalences to the Applicant Project Partners' population, which will be served with Telemedicine Triage exponentially represents a very large number of unnecessary ER visits and inpatient stays which can be prevented.¹⁰

For our new project, we are conservatively estimating that we can prevent 45% of those visits with this service, or between 7,970 and 9,272 visits per year that will be avoided — and that number grows to between 10,627 and 12,363 ER visits avoided annually if we prevent 60% of visits for the project's population. The I/DD ACO data, along with the experience of the CP of NYS telemedicine triage program to date, demonstrates that the savings this project offers creates a more financially sustainable system of integrated care.

Moreover, the COVID crisis laid bare the interconnection of the OPWDD certified residences and the acute care system's dependence on those services to support a highly vulnerable population in their homes without accessing the specialty and acute care system. Our telehealth project proves the investment works to ensure and control for inordinate use of the ED and/or lack of integration with the emergency, acute, crisis management, and urgent care centers across the State.

Given the significance of the workforce shortage in the I/DD sector — prior to COVID we were at 15% statewide, and during COVID we have reached 25% staff vacancy rates¹¹ — this model of accessing health supports truly impacts the quality of life and improves access to health care statewide by integrating the delivery of health services for a vulnerable population in the most efficient setting. For each ER visit, a staff member is needed to accompany the person supported with I/DD which exacerbates staffing shortages, drives additional overtime and staff burnout and turnover — components of a system that is unsustainable.



Finally, we believe the applicability of the work done in telehealth — and many of the activities CP is working on — will be applicable to a broader population and thereby increase its relevance to policy makers. Consider that of 75 million baby boomers, half will have a disability or chronic condition related to aging. The models of the disability community should inform policy decisions when that group would easily double who might need these services. We believe the models in the I/DD community will have increased relevance and impact, if adopted, when expanded to the general population with our aging in place and community integration approach vs. the more costly institutional supports for seniors acquiring similar disabilities.

RECOMMENDATIONS:

- **Incorporate the telehealth medical triage model in certified residential funding as a key clinical component.**
 - **Develop regulations and payment structures to support expansion of telehealth for triage, primary care, behavioral health and specialty services.**
 - **Support the sharing of triage and other telehealth data across Medicare, Medicaid, and other payors to better analyze and understand the impact of telehealth; to the extent possible, look to use the data to identify and develop best practices and protocols in the care and treatment of people with I/DD.**
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Mental Health

More than a decade of research has demonstrated that co-existing mental disorders in people with I/DD may be more prevalent than known or generally understood. To date this science base has not effectively driven significant changes in practice. The gaps in diagnosis and treatment still exist. The burden of this failure falls to the people and their families. Providers have long recognized that more than 50% of their clinic patients and residents have co-existing mental health diagnoses. In 2021, CP of NYS has engaged an expert in the field of mental health, former OMH Commissioner

Dr. Sharon Carpinello, to assist us in assessing our needs and prioritizing the I/DD system's best path forward to address these issues in separate health systems. The decision to make this investment grew from a growing unease from I/DD community providers concerning issues related to mental health services, including access to care, supply and demand, clinical knowledge base, treatment practices, polypharmacy, use of best practice guidelines, managing mental health crisis, issues of personal respect and suicide prevention. With the onset of COVID-19, these issues have only been exacerbated.

CP of NYS 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. We are in the process of developing recommendations reflecting the outcomes of a series of listening sessions. A report, *At The Crossroads: People with I/DD and Co-existing Mental Disorders*, will be released separately in 2022.

What does the term behavioral health mean?

The term “behavioral health” in this context means the promotion of mental health, resilience, and wellbeing; the treatment of mental and substance use disorders; and the support of those who experience and/or are in recovery from these conditions, along with their families and communities.

Advancing health equity involves ensuring that everyone has a fair and just opportunity to be as healthy as possible. This also applies to behavioral health. In conjunction with quality services, this involves addressing social determinants, such as employment and housing stability, insurance status, proximity to services, culturally responsive care – all of which have an impact on behavioral health outcomes.¹²



COVID and I/DD Providers' Place in The Health System

There are 140,000 people with I/DD enrolled in the State OPWDD system and another estimated 300,000 people with I/DD across the state. They tend to be high users of the health care system: “people with I/DD have higher prevalence of co-morbid risk factors (i.e., hypertension, heart disease, respiratory disease, and diabetes) often associated with poorer COVID-19 outcomes”¹³ and the mortality rate for COVID was 2.4 times that of the typical population.

Part of the reason the rate of infection is higher than in the general population is due to the large number of congregate settings operated by OPWDD licensed and funded agencies across the State.¹⁴ But what became particularly obvious under the initial phases of COVID is that the disability programs and services were not well understood as a critical part of the health system by the lead policy makers with the Administration and DOH. Our providers had to explain time and time again why sending someone with COVID back to a residence with healthy people in it and staff coming in and out on a regular basis was not a good idea. Further, disability providers had to struggle to be recognized as “essential workers” despite the 24/7/365 nature of our residential programs and we were not among the priority providers in the health system to access PPE. On top of that, more than a few of our medical directors were forced to have to advocate for making people with I/DD a priority in the decision-making process when there was limited access to ventilators in many hospitals.

Beyond COVID, people with I/DD are often not treated well in the ER due to communication and/or behavioral challenges, and many hospitals across the State require our staff to stay with the patient throughout the hospital stay — despite clear indication from DOH and OPWDD that certified residential providers are not paid for that coverage. Even more troubling is that when individuals with I/DD are brought to the ER, they have a higher risk of being admitted to the hospital, resulting in potentially increased risk factors. Acute care providers are ill-equipped to support people with I/DD and there is no funding for disability agencies to send staff to the hospital — the dearth of alternate level of care or specialty services across the State have created a backlog in some hospitals as discharge to our residences often is not a real option given the supports needed to be safely discharged.

Policymakers need to better understand the role the I/DD provider community plays as part of the health system. The clinical supports provided in a residential, day program or the I/DD focused clinic have profound impacts on the way people with I/DD use urgent, ER, long-term and acute care services in traditional models. We believe the opportunity for payment model exploration and improved integration with the health system must be seized upon immediately to correct this.

RECOMMENDATIONS:

- **To ensure equitable access to health care, the newly created Office of the Chief Disability Officer must be empowered to support a systemic review, the identification of gaps in the health system for people with I/DD, and to make recommendations that transcend DOH/OPWDD/OMH/SED/OCFS program barriers to ensure equitable access to health care.**
 - **Using Medicaid payment analytics across all sectors, the NYS Division of the Budget (DOB) must calculate the savings across all budget categories — what may be an expense for one agency may generate considerable savings in others. People with disabilities are complex, as is their impact on the NYS budget.**
 - **The upcoming NYS 1115 Health Equity Waiver should be used to include pilot model options, such as PACE-like models among others, to ensure people with I/DD have equitable access to care.**
-

Community Health Outreach Project (CHOP)

As has been noted, gaps in the health care system for the typical population are even more profound for people with higher needs, particularly those with I/DD, and the current system fails people with I/DD over and over again. This is due to utilization management controls, which are geared to the typical low need population, don't contemplate people with high needs health requirements, approvals for treatments/items and fail to understand that a particular high cost service/item is not only justifiable but is cost efficient for those with I/DD. To address those "gaps in system funding,"

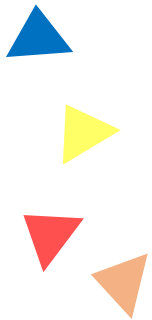
CP of NYS has been fortunate to have the support of the NYS ELKS which has provided financial support to our Affiliates for more than 60 years to ensure people with I/DD could get to doctor's appointments, were able to complete their eligibility paperwork, had a ramp built that kept them in their homes, etc.

CHOP IMPACT STATEMENT – During the past year, JOEY was hospitalized 9 days and MATT was hospitalized 27 days, both with hypothermia. It was determined that Bair-Hugger gowns, which can easily be worn while sitting upright in a wheelchair, and Bair-Hugger single-patient use temperature sensors, which provide accurate core temperature readings from the forehead, were needed for Joey and Matt. CHOP funds were used to purchase a 3-month supply, and since they began using these products, Joey and Matt have a lot to be happy about since they have had ZERO hypothermia-related hospitalizations!

This “extra” funding has been critical because the current system’s funding fails to meet the entire needs of this group who might otherwise be left in their homes or require higher cost certified settings to ensure their health and safety. For years, our Affiliates and all disability providers have focused on the whole person, the factors that keep them healthy — access to care, a home, nutrition, transportation, etc. — the social determinants of health which this grant supports.

In 2020, CP of NYS obtained funding from the Mother Cabrini Health Foundation to specifically get to the health needs of people with I/DD that

current funding did not support. With that funding, we created the Community Health Outreach Project (CHOP) which is structured to ensure we are considering the social determinants of health as we try to meet the health needs of people with I/DD, when other funding is not available. With our 2020 funding in 14 counties surrounding the Albany area, we were able to provide a broad array of services and items to improve the health of people with I/DD. The items needed included hearing aids (yes, Medicaid covers them but only every 3 years), warming blankets needed to maintain body temperature, shower chairs, and a broad array of items that truly made a difference in ensuring people with I/DD have the access to what they need to ensure their health. (To see some of the highlights and case studies, click [HERE](#).) For 2022, we are thankful that the Mother Cabrini Health Foundation again supported this initiative — this one-year grant will be on a statewide basis — and will allow us to “fill the gaps” for people with I/DD all across the State for whom the system has not met their needs.



While it's terrific that we have a temporary funding source to meet the health needs, the broader question remains: why is the funding for this group falling short of meeting their health care needs? Our experience tells us that because our population of people with I/DD fall outside the typical use/need parameters, they are not included in the policy considerations. There is no centralized health status approach across New York State funding entities, and we ultimately have gaping holes in the supports for what is arguably our highest need, highest cost population. The result is fractured delivery of care, and higher system costs that could be avoided with a more centralized approach to disability health services.



HOLES IN THE SYSTEM . . .

A SAFE HOME – Greg, diagnosed with cerebral palsy and spinocerebellar ataxia, uses a wheelchair exclusively. Recently, Greg's vertical wheelchair platform/lift stopped working, so he was unable to leave his home for program. Additionally, he would not be able to evacuate in the event of an emergency. Medicaid would not cover the repair costs to the lift, so CHOP funds were used. The lift was repaired within a few days, and Greg is able to resume his activities outside of the home.

RUNNING WATER – Charles and his mother (caregiver) have been without running water for over a month due to an issue with the pump that operates their well. Since they cannot shower, they are purchasing gallon jugs of water to bathe. Additionally, they are unable to flush the toilet unless a gallon of water is poured in. Purchasing gallons of water has put an additional financial burden on the family. CHOP funds were used for a new pump, which was installed on March 17, 2022.

QUALITY OF LIFE – Greg is diagnosed with cerebral palsy and scoliosis. Being very tall with little trunk control, Greg was having difficulty showering and toileting. After extensive observations and consulting, his occupational and physical therapists determined that the Rifton Hygiene and Toileting System were a great option for him. Unfortunately, Medicaid would not cover the cost, so CHOP funds were used to purchase this equipment. Greg's hygiene, quality of life, and overall spirit has improved greatly as a result of the new equipment.

RECOMMENDATIONS:

- **OPWDD/DOH must work with CP of NYS to review the CHOP applications to identify areas where the State funding falls short of health needs of the I/DD population. Together we must begin to work through the gaps in environmental/vehicle modifications, UM/UR limits, and other barriers to whole person health that the CHOP project identified.**
 - **Use the analysis of the needs identified by the CHOP program to inform policy recommendations for TRAIID project expansion of assistive technology uses.**
 - **Evaluate establishing a state funding option, similar to the way the CHOP program works now; to fill in the gaps and ensure the maintenance of people with disabilities' health.**
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Dually Eligible Population

Another perennial concern/barrier for CP of NYS in our advocacy has been the fact that many of the patients/people we support are dually eligible (Medicaid/Medicare). The number of dually eligible individuals with I/DD who are supported by OPWDD funding statewide exceeds 50%. We understand the State may not fully optimize the Medicare component in any savings or cost avoidance generated, but is that truly a sound public policy argument for not moving forward to improve the coordination of care for this vulnerable population? Shouldn't the quality of care, access to care and the quality of life of people with I/DD be central to our policymaking? And don't forget, at the same time as the approach to disability health policy is improved, the quality of life/health outcomes improve, as does the removal of system inefficiencies.

The challenge in developing new models of care, and integrating housing, health, and other services is that Medicare and Medicaid do not have clear lines to trace the impact and savings/cost avoidance from various health or long-term care services policy changes. What is clear is that federal involvement/cooperation is needed for NYS to move forward to ensure that

counties, the state and all the different levels of government, and different programs, pay for different elements of the needed range of services in a coordinated manner. And while Medicaid has more experience in covering a range of services, it might well be that Medicare should be the source of all funding for these activities. We recommend that New York State begin working with providers and the federal government to look at 1115 waivers to pilot ways Congress could support a truly innovative disability funding model in New York State.

RECOMMENDATIONS:

- **Coordinate a NYS approach to finding savings for the general disability population; submit an 1115 waiver that contemplates state sharing in the savings generated on the Medicare program as part of this pilot.**
 - **Develop and make available a Medicare/Medicaid crosswalk to claims data for this population.**
 - **Work with CP of NYS and others who have done work on database analysis and structure to develop a truly beneficial data repository for disability health activity and study.**
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CONCLUSION/RECOMMENDATIONS SUMMARY

CP of NYS and its Affiliates have tried in multiple ways to work toward erasing the barriers/challenges to health equity for people with I/DD. Unfortunately, some of the largest barriers remain. What is needed is a full-scale, multi-system assessment of the barriers to improving access and health outcomes for people with I/DD in New York State. We believe partnering with our state leaders at this time is critical — to remove the agency-specific funding and regulatory controls that prevent efficient, effective and deliberate use of public funds for a high need population. We have numerous ideas and specific actions that we believe will work to move the disability movement forward in the area of health equity. We ask that the administration and our agency partners — OPWDD, DOH, SED, OMH, and OCFS — work with us and our legislators to move the innovation necessary forward to realize our goal.

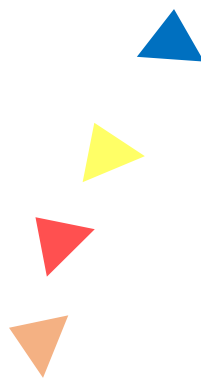
Supporting New Yorkers with disabilities — the complex and frail, as well as those at the high end of ability — will reduce the disproportionate cost associated with people who are not curable or sick, but complex and challenged. The following are some first steps toward this goal we hope will be considered. In the meantime, CP of NYS' Medical Directors Council, our Clinic Directors, and other resources are available to begin the work with our policymakers in New York.

General Recommendations

In addition to/in coordination with the specific recommendations stated above, these are the general concepts we have identified as necessary to truly ensure equitable access to health care for the I/DD population in NYS:

FEDERAL ACTIONS:

- **Update The Medical Necessity Definition At The Federal Level** – Medical necessity definition should consider chronic conditions and multiple diagnoses and not a RESTORATIVE/CURATIVE mentality (does not work for the I/DD population).
- **Medically Underserved Designation** – At the federal level, establish the disability community as part of the medically underserved which will open access to grant and other federal funding options to support this high need population.
- **Pilot For I/DD Under An 1115 Waiver** – Submit a pilot model which tests payment options, care models, etc. which address the issues identified in this document.
- **Expand basic training courses on disability competencies** for first responders, emergency technicians, social services/child protective personnel and families to ensure competency with providing disability support.



SPECIFIC STATE ACTIONS / HALLMARKS OF AN EFFECTIVE PLAN FOR I/DD HEALTH CARE:

- **Coordination** – Ensure coordination between Medicaid and Medicare programs — third party insurance if possible — that recognizes the WHOLE person and our lifelong needs (federal above as well as what is under the State’s control). This includes INTEGRATING disability health issues with other funding systems:
 1. **Behavioral Health** – The prevalence of BH-I/DD overlap has been known — 54% of people have a co-existing disorder; as an example, need routine screening for depression.
 2. **Education/Employment**
- **Flexibility** – The system must respond to transitions in life — typical markers (graduation from high school – at 21) and from community to old age aren’t handled well; we need to also allow for changes in condition/progression of diagnoses — fluctuations are to be expected.
- **WHOLE Person Needs; Social Determinants of Health** – Housing, transportation, employment — we get to pieces of people’s lives, but we need to look at how we support the entire person.
- **EQUITABLE Access to Care:**
 - Ensure a pool of informed/educated and highly capable clinicians
 - Physical plant accommodations
 - Review and adjust UM/UR thresholds that recognize higher needs
 - Increased flexibility for use of telehealth — with COVID we have found that we have fewer missed appointments/better oversight due to those flexibilities.

In short, we are asking that NYS acknowledge that the high need, high cost, and complex I/DD population does not fit into our current funding and regulatory constructs and commit to transitioning to a systemic approach of supports and services.

This is not only the right thing to do to improve the quality of life for people with I/DD, the efficiency and cost-savings make it the financially responsible thing to do.

We know we need partners to get this done, and CP of NYS is here and ready to begin work on any and all of these proposals.

SOURCES

1. World Health Organization (WHO) Annual Report, November 2021
2. Healthy People 2020, based on 2015 CDC data.
3. World Health Organization (WHO) Annual Report, November 2021
4. (Panko Reis et al 2004; U.S. Department of Health and Human Services 2003; Institute on Disability and Development 2003). – From The Surgeon General's Call to Action to Improve the Health and Wellness of Persons with Disabilities. Office of the Surgeon General (US); Office on Disability (US). Rockville (MD): Office of the Surgeon General (US); 2005.
5. U.S. Office of Disease Prevention and Health Promotion; Healthy People 2020, Disability and Health
6. Bateman, Hobaug, et. al. 2021 Mercer Healthcare Labor Market report
7. How Equity-Oriented Health Care Affects Health: Key Mechanisms and Implications for Primary Health Care Practice and Policy, Ford-Gilboe, Wathen, et al., 22 October 2018
8. Matt Holder, MD, MBA, FAADM, Co-Founder of the American Academy of Developmental Medicine & Dentistry (AADMD), presentation at the AADMD Annual Education Conference in 2019, in Rochester, NY, in a workshop called "The Future of Care for People with IDD"
9. Matt Holder, MD, MBA, FAADM, Co-Founder of the American Academy of Developmental Medicine & Dentistry (AADMD), presentation at the AADMD Annual Education Conference in 2019, in Rochester, NY, in a workshop called "The Future of Care for People with IDD"
10. AICNY – DATA 2019
11. COPA 2018 Data/NYDA 2021 Vacancy Surveys
12. Substance Abuse and Mental Health Services Administration (SAMHSA); Behavioral Health Integration and Behavioral Health Equity definitions; SAMHSA 2022.
13. COVID-19 outcomes among people with intellectual and developmental disability living in residential group homes in New York State; Landes, et.al. 2020
14. Risk Factors Associated With COVID-19 Outcomes Among People With Intellectual and Developmental Disabilities Receiving Residential Services; Landes, Turk, Damiani, et. al, 2021



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**Prioritizing Health Equity for People with I/DD in NYS:
The Smart Thing *and* The Right Thing To Do
April 2022**

SUMMARY OF RECOMMENDATIONS

Key challenges to health equity for people with I/DD include:

Clinician Training/Readiness Recommendations

- Clinicians must receive incentives to retire their educational debts for working with individuals with I/DD.
- Development of Acute Care Clinician Training Requirements — Hospitals should not be allowed to medicate and release patients with behavioral health needs because there is no “system” to support their needs. A better understanding of the I/DD population, training, and care protocols are required.
- Clinicians training in complex care and those receiving specialty I/DD training should be provided access to federal and state education loan forgiveness programs.
- To ensure that complex needs are supported prior to issuance of any new health policies and regulations, DOH and OPWDD should access CP of NYS Medical Directors’ Council and related I/DD health issue expertise in the review and development of health policy.
- To ensure health equity discussions include the I/DD community, CP and the I/DD field’s clinical expertise should be incorporated as part of the regional 1115 Waiver discussions.
- To ensure competency with providing disability support and care, first responders, emergency technicians, social services/child protective personnel, and family training should be expanded to include disability competencies.



Medical Complexity/Centers of Excellence Recommendations

- Fund the Centers of Excellence in the Care and Support of Children with Autism Spectrum Disorders and Other Complex Needs or a larger focused model on complexity. Understanding complexity will help drive the development of protocols that will both improve care and reduce or prevent additional costs.
- Implement the recommendations of the CP of NYS data repository to ensure access to information across complex populations. NYS must dedicate Medicaid/DOH program staff to centralize the clinical analysis and evaluation of the clinical supports/ interventions in conjunction with the disability clinicians who understand the population.
- Align data from the Centers of Excellence, CP of NYS telehealth project, and other evolving research for the development of disability care research priorities.
- Expand the use and support of the clinical screening tools developed under the Centers and fund training and clinical resources to implement the tools statewide.
- Regularly convene the Centers' experts with cross-sector State agencies (DOH, OPWDD, OMH, SED, OCFS) and other providers to review the progress being made and work being done to ensure that the advancements identified are incorporated in health practice across the State.



Telehealth Recommendations

- Incorporate the telehealth medical triage model in certified residential funding as a key clinical component.
- Develop regulations and payment structures to support expansion of telehealth for triage, primary care, behavioral health, and specialty services.
- Support the sharing of triage and other telehealth data across Medicare, Medicaid, and other payors to better analyze and understand the impact of telehealth; to the extent possible, look to use the data to identify and develop best practices and protocols in the care and treatment of people with I/DD.



Mental Health Recommendations

We are in the process of developing recommendations which reflect a series of listening sessions. A report, At The Crossroads: People with I/DD and Co-existing Mental Disorders, will be released separately in 2022.



COVID and I/DD Providers' Place in The Health System Recommendations

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