



Testimony of

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Access to mental health and developmental disability services and supports

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Good afternoon. My name is Alice Bufkin and I am the Director of Policy for Child and Adolescent Health at Citizens' Committee for Children of New York, Inc. (CCC). CCC is a 74-year old independent, multi-issue child advocacy organization dedicated to ensuring that every New York child is healthy, housed, educated, and safe.

I would like to thank Chair Gunther, as well as all of the members of the Assembly Standing Committee on Mental Health and Developmental Disabilities, for holding today's hearing, and for your long-standing commitment to improving outcomes for children and families.

In January, the State will be launching many of the core components of children's behavioral health reform, making this a critical time to examine children's access to behavioral health services. The transition of children's behavioral health services to Medicaid managed care provides an unprecedented opportunity to expand preventive, family-focused services to more children in the community. However, substantial work remains to ensure this transition is successful, and to address broader issues related to capacity and unmet need.

This is also a critical time to address supports for children with developmental delays and disabilities. Our state is experiencing a crisis in our Early Intervention program, which provides evaluations and services to infants and toddlers with significant developmental delays or disabilities and their families. Due largely to years of inadequate reimbursement rates, several providers have begun shutting their doors or placing children on waitlists. This emergency must be addressed before it becomes even more widespread.

We are enormously grateful to this Committee for providing a forum to examine these important systems. Decades of research has shown that providing preventive services to children is the key to avoiding the need for more intensive services later in life. By investing in strong systems, our state can impact the health and wellbeing of children and families for a lifetime.

My testimony today will first focus on the transition of children's behavioral health services to Medicaid managed care and the expansion of new home and community-based services. I will then turn my attention to this hearing's charge of examining access to developmental disability services and supports, where I would like to highlight the crisis currently facing the Early Intervention system.

Transition of Children's Behavioral Health Services to Medicaid Managed Care

Our state's behavioral health system has consistently struggled to meet the needs of children in need of mental health and substance abuse services. Detailed data is difficult to obtain, but it is clear that the need for services far exceeds the supply.

According to the United Hospital Fund, approximately 220,000 of the two million children enrolled in Medicaid receive substance abuse or mental health services¹. However, numerous additional families wait months for an appointment with a psychiatrist or child therapist. Parents without access to preventive services are often forced to bring their children to emergency rooms in moments of crisis, or cycle through children's psychiatric units in New York hospitals. Only a

¹ Kennedy-Shaffer, Lee and Chad Shearer. "Understanding Medicaid Utilization for Children in New York State: A Data Brief." United Hospital Fund. July 2016.

fraction of children with a serious emotional disturbance (SED) receive specialty mental health treatment.²

Medicaid redesign offers an unprecedented opportunity to provide preventive, community-based services that catch problems earlier, before they require more intensive services. However, inadequate investment and years of delay put this transformation in jeopardy.

Work to transform the children's behavioral health system began in 2011, before undergoing a series of delays. Heading into the 2018/2019 budget cycle, children's behavioral health providers were preparing for the transition to managed care and the expansion of services. However, the SFY 2018/2019 Executive Budget did not include funding for the transition or new services, threatening to derail the state's progress. CCC sincerely thanks the Assembly for its extensive work fighting for Capital funds for the transition. The Assembly's commitment to this funding – as well as the advocacy of numerous parents, providers, and other stakeholders – helped ensure that \$15 million for transition funding was included in the Final Budget.

The children's transition includes a number of core components, including the movement of all 1915(c) Home and Community Based Services (HCBS) Children's Waiver members to Health Homes; the movement of exempt Medicaid services and populations to Medicaid managed care; and the consolidation of 5 different HCBS Waiver Programs into a single HCBS program with a uniform array of 11 services.

Among the most transformative aspects of the transition is the introduction of six new services for children, known as Children and Family Treatment and Support (CFTS) Services. Previously only available to high-needs children served through waiver programs, these services are now meant to be available to all Medicaid eligible children under the age of 21 who meet medical necessity criteria.

At their core, these services seek to intervene early to prevent the need for more restrictive or higher intensity services. These evidence-based services are provided in homes and communities where children and families live. Services are culturally competent and trauma-informed, and must involve communication and coordination with family, caregivers, and/or legal guardians.

Three of these new services – Other Licensed Practitioner (OLP), Psychosocial Rehabilitation (PSR), and Community Psychiatric Treatment and Supports (CPST) – are being rolled out in January 2019. A fourth service, Family Peer Support, is scheduled for implementation in July 2019, and the final two services (Youth Peer Support and Training, and Crisis Intervention) are scheduled for January 1, 2020. It is important to note that only the first four of these services have CMS approval, and rate approval for these four services is still pending.

With these new services, more children and adolescents will gain access to services that help identify needs early, focus on recovery and resilience, prevent the need for higher-end services, and support the child at home and in community settings. For instance, the Other Licensed Practitioner (OLP) service enables non-physician licensed behavioral health practitioners to prescribe, diagnose, and/or treat individuals. A child with mobility challenges might meet with an OLP and receive psychotherapy in the home or at school. Under the Community Psychiatric Treatment and Supports service, a CPST provider might visit an adolescent's family at home to work

² New York State Office of Mental Health. "Health Home Serving Children Implementation Policy Bi-Weekly Webinar." July 19, 2017.

collaboratively on a treatment plan to address the negative effects of the adolescent's alcohol and drug use.

Because contract awards will not be released until December 7th, it is difficult to say at this stage whether current investments in the system are sufficient to fully implement the new services. However, the inclusion of transition funding in the SFY 2019-20 budget will be essential to supporting these critical new services, as well as ensuring a seamless transition to Medicaid managed care. CCC strongly appreciates the Governor's inclusion of transition funding in his SFY 2019-20 projected budget, and looks forward to working with the Administration to ensure the transition proceeds under the proposed timeline with no further delays.

Recommendations:

After years of delay, the state is on the verge of making transformational changes to the children's behavioral health system. However, additional work remains to ensure that this transformation ultimately provides more children with timely access to preventive care. Below are recommendations for how the state can improve outcomes for children.

- **Recommendation 1: Provide an additional six months of enhanced rates for Children and Family Treatment and Support Services.**

As part of the funding allocated to the transition, providers will receive an enhanced rate for the new services during the first six months after their introduction. At the end of six months, this rate will decrease, before eventually falling to the base rate after 12 months of operation.

This enhanced rate is essential for ensuring a successful launch of new services, providing support for behavioral health providers as they adjust to a new array of services and conduct community outreach. Enhanced rates will cover startup costs, such as adjusting to the transition from fee-for-service to managed care, and covering staff costs during the slow ramp-up period as families and communities become aware of new services.

While this enhancement is important for ensuring the success of the new services, a number of challenges make clear that six months of enhanced rates is insufficient.

First, the original timeline for system transformation has been substantially modified as a result of decisions by the Centers for Medicaid and Medicare Services (CMS). The original proposal to CMS was to consolidate the original 1915(c) HCBS Waivers into a single 1115 waiver, and to roll out CFTS Services prior to the waiver transition. However, CMS rejected this proposal in May, forcing the state to move towards seeking concurrent consolidated 1915(c) and 1115 waiver authorities.

In addition, children's behavioral health providers are required to crosswalk every child in waiver services to CFTS services by January 18th. This means providers will first need to focus their attention on transitioning children currently getting services through the waiver to the new CFTS services. An unfortunate side effect of this timeline is that there will be a delay in some providers' ability to conduct outreach and enroll non-waiver children from the community, including those who might most benefit from CFTS services.

As a result of the timeline changes, the state will need to implement three major reforms in January: 1) Implementing the first three of the new CFTS services; 2) Transitioning children in the old waiver to new waiver services; and 3) Transitioning children to Health Homes. Providers will be

tasked with undertaking a series of substantive transitions at the same time, limiting their ability to conduct outreach to children in the community who could most benefit from new services.

These challenges are made more difficult by widespread workforce shortages. Though comprehensive data is difficult to obtain, many of our partners in provider networks report six-month staff turnover in the range of 40%, with 10% vacancies. Without enhanced rates, recruiting and retaining providers to offer these critical services will be increasingly difficult. Moreover, the base rates themselves may be insufficient to provide services. For instance, providers report that travel costs are severely under-estimated in the proposed base rates.

To achieve the goal of expanding home and community-based services, communities, families, and referral sources need to be aware that new services are available. Providers need to have staff in place by January, even though enrollment will start out slow as families and communities learn about the new services.

Making large systems transformations takes time, especially when the state is facing challenges from federal implementation changes and workforce shortages. In order to achieve a seamless waiver turnover and ensure the state successfully rolls out new CFTS services, **CCC recommends an additional six months of the enhanced rates for CFTS services beyond what is currently planned. As with the initial enhancements, this should require an investment of \$10 million.**

- **Recommendation 2: Improve data collection related to service capacity and provider workforce.**

Among the greatest challenges to determining the impact of the state's transition of children's behavioral health services is a lack of sufficient, comprehensive baseline data on the gap between the number of children who need behavioral health services, and those who actually receive them.

In 2012, CCC conducted one of the few analyses of the gap between the need for treatment slots and the number of treatment slots available for children in New York City. Through our analysis, we found that there were only treatment slots for 1% of children ages 0-4 and 12% of children ages 5-17 who have treatment needs within the three boroughs we examined.³ This analysis underscores the need for detailed, regularly-updated data to identify gaps in access.

Estimates on the gap between capacity and need remain frustratingly sparse, making it difficult to assess the true unmet need within the state. **We therefore urge the DOH, OMH, OPWDD, and OCFS to collaborate to improve the collection and dissemination of data on children receiving behavioral health services.** By establishing a baseline of children served prior to the transition, the state can better monitor the impact of these large systems changes. This data is invaluable for lawmakers, advocates, providers, and other stakeholders seeking to identify how to best increase access in a strained and under-resourced system.

In addition to the need for more data on children served, there is need for more data on workforce availability. Though we know the workforce shortages are widespread, it is difficult to quantify the extent of the problem without more robust data collection from the state.

³ Citizens' Committee for Children of New York. "New York City's Children and Mental health: Prevalence and Gap Analysis of Treatment Slot Capacity." January 2012.

Last year, Senator Lavelle introduced S8204, which would have required additional reporting and data collection on health care practitioners. This bill would have required 40 categories of health care practitioners to report information as part of their registration/re-registration process. Reportable information would include the type of setting where the practitioner practices and their geography. This data would help inform the state whether, where, and how behavioral health professionals are practicing, and this bill would have made the data available in aggregate form on the DOH website.

Modeled after a similar requirement for Nurse Practitioners enacted in the 2014-15 budget, this bill would have taken an important step towards tracking and reporting on where services are being provided. **CCC urges support for additional data collection that would help the state identify and address the workforce shortage for children's behavioral health services.**

- **Recommendation 3: Increase outreach efforts to educate families and communities about the introduction of new services.**

Given the great opportunity these new CFTS services will offer, it is critical that families be made aware of their existence. It is also important that community partners and referral sources are well-informed of the services so they can help identify and refer children who would particularly benefit from receiving them. Without robust education and outreach, providers will struggle to ramp up services and accurately determine how many children they will serve. **We urge DOH to provide additional assistance with outreach and advocacy efforts to increase community education around CFTS services.**

- **Recommendation 4: Investigate how non-Medicaid children would benefit from receiving new CFTS services.**

Currently, CFTS services are provided only to children eligible through Medicaid. However, non-Medicaid children – particularly those in Child Health Plus – would benefit equally from having access to new CFTS services. 368,160 children receive their health and mental health insurance through the federal CHIP program. **We urge the Legislature to investigate steps to extend these services to children outside the Medicaid system.**

- **Recommendation 5: Invest in greater service capacity.**

The introduction of new CFTS services is an important step towards expanding access to behavioral health services and investing in prevention. However, the transition of children's behavioral health services into Medicaid managed care cannot by itself address widespread issues with waitlists, workforce shortages, and capacity challenges.

Addressing capacity will necessitate substantial investments from the state in the children's behavioral health system. These investments will lead to long-term savings in the child welfare, juvenile justice, homeless services, and education systems. More importantly, a well-resourced system of care will mean more children will receive the services they need to prevent the need for more intensive services later in their lives.

New York State must invest in a system that serves children of all ages, and that provides access to a full continuum of services, from preventive care to high-end services. Only by doing so can we avoid crisis and ensure more children have the opportunity to thrive in schools, at home, and in their communities.

Again, CCC is enormously grateful to the Assembly for all its work ensuring that this transition will occur, and for holding this hearing to determine how the state can fulfill the promise of the expansion of children's behavioral health services.

Access to Developmental Disability Services for Children

CCC thanks the Assembly Standing Committee on Mental Health and Developmental Disabilities for focusing attention on the need for services and supports for individuals with developmental disabilities. As this Committee and the State seek to support a coordinated system of care for children, it is imperative that the State address the crisis currently unfolding for infants and toddlers who receive Early Intervention services in New York.

A series of recent articles has underscored long-standing challenges facing the EI system as a result of under-investment at the state level.⁴ For years, many EI providers have struggled to keep their doors open in the face of insufficient reimbursement rates and administrative burdens, jeopardizing their ability to continue serving infants and toddlers with developmental delays and disabilities. Now, Monroe County has become the first county in the state to put children showing signs of developmental delay on waiting lists before they can be evaluated for services. Less than half the number of service coordinators remain in Monroe County compared to 15 years ago.⁵

Though recent media has focused on the challenges facing Monroe County, these difficulties are reflected throughout the state. New York must act now to prevent these challenges from becoming more widespread and further threatening children's access to services.

Early Intervention provides evaluations and services to children age birth to three with developmental delays or disabilities. Professionals work as a team with families to address the unique needs of each child. As providers are working with the child, parents/caretakers also learn skills and strategies help their children grow and develop. These services can be provided in the home, in a child care setting, or in whatever setting is natural for the child.

Decades of research have shown that children's earliest experiences play a critical role in brain development. Intervening in the first few years of life can change a child's developmental trajectory, leading to positive outcomes across health, language and communication, cognition, and social/emotional domains.⁶ Early intervention has been shown to lead to improvements in verbal

⁴ Murphy, Justin. "County Announces Waiting List for Early Intervention, Blames State." *Democrat & Chronicle*. November 27, 2018. <https://www.democratandchronicle.com/story/news/2018/11/27/monroe-county-waiting-list-early-intervention-lawsuit/2124145002/>; Noonan, Emily. "Families and Agencies Say There is a Crisis in Care for Early Intervention Services in Monroe Co." *Rochester First*. November 27, 2018.

<https://www.rochesterfirst.com/news/local-news/families-and-agencies-speak-up-at-legislature-committee-meeting-about-early-intervention/1623319990>; Dahlberg, Brett. "Monroe County a 'Canary in the Coal Mine' for Looming State Crisis in Early Childhood Therapy." <http://www.wxxinews.org/post/monroe-county-canary-coal-mine-looming-state-crisis-early-childhood-therapy>

⁵ "Children Facing Crisis in Statewide Service Shortage." WHEC. November 27, 2018.

<https://www.whec.com/news/children-facing-crisis-in-statewide-service-shortage/5159203/>

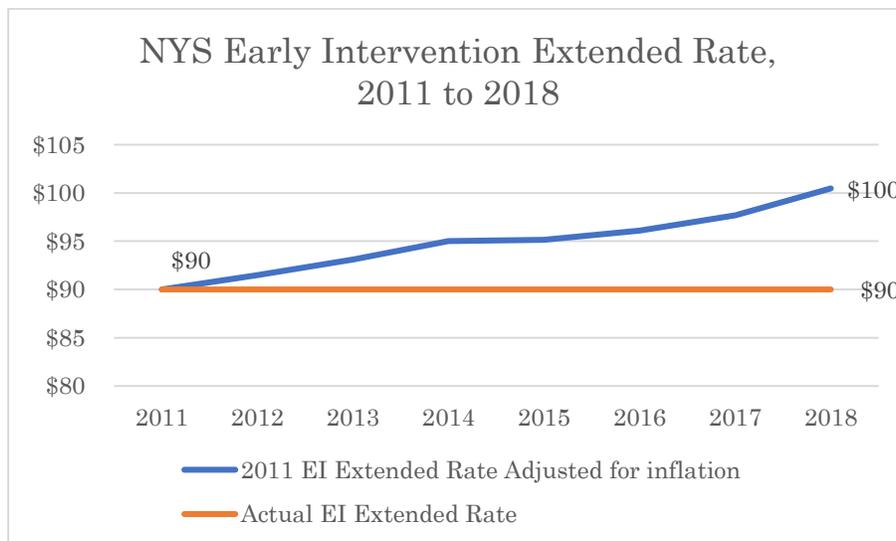
⁶ "The Importance of Early Intervention for Infants and Toddlers with Disabilities and Their Families." The National Early Childhood Technical Assistance Center. July 2011.

<http://www.nectac.org/~pdfs/pubs/importanceofearlyintervention.pdf>

abilities, language development, and overall cognitive performance.⁷ Early interventions help children become school-ready, and have widespread impacts on children, families, and communities across a child’s lifecourse.⁸

Despite the critical role that Early Intervention plays in the lives of young children, New York State’s reimbursement rates for EI providers are actually lower than they were when the program began more than 20 years ago. Instead of providing cost-of-living increases, the State cut the EI service rate for home- and community-based services by 10% in April 2010, and cut the reimbursement rate for all EI services by an additional 5% in April 2011. The rate has remained unchanged since then.

The Extended Home and Community Based Individual Collateral rate is the rate commonly billed for Occupational Therapy, Physical Therapy, and Speech Therapy. The chart below indicates the average rate New York State providers would be paid today if rates had kept pace with inflation after 2011.

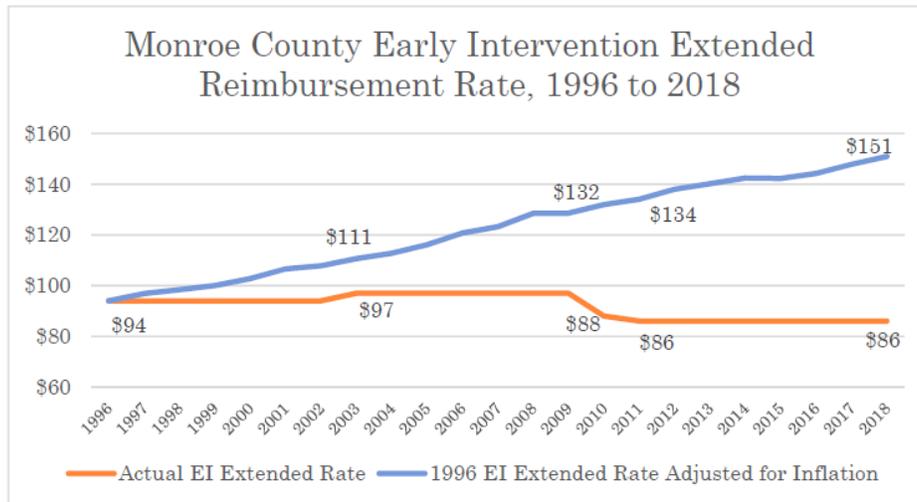


This gap is even larger when compared to rates from 1996, when the program first began. For instance, this rate was \$94 in Monroe County in 1996, but has fallen to \$86 in 2018. According to The Children’s Agenda, this rate would be \$151 today if adjusted for inflation.⁹

7 McCarton CM, Brooks-Gunn J, Wallace IF, et al. “Results at Age 8 Years of Early Intervention for Low-Birth-Weight Premature Infants. The Infant Health and Development Program. *JAMA*: 277(2). 1997.

⁸ “The Importance of Early Intervention for Infants and Toddlers with Disabilities and Their Families.” The National Early Childhood Technical Assistance Center. July 2011. <http://www.nectac.org/~pdfs/pubs/importanceofearlyintervention.pdf>

⁹ Nabozny, Pete. *Valuing Early Childhood Developmental Services: Reimbursement Challenges for Early Intervention and Preschool Special Education Services in Monroe County*. The Children’s Agenda. April 2018.



In addition to reducing rates, the State implemented a new process for seeking reimbursement, placing significant administrative burdens on EI service coordinators, individual providers, and agencies. As a result, experienced, high-quality EI providers have shut their doors or stopped taking EI cases, making it difficult for children in certain areas to access much-needed high-quality services in a timely manner. Many providers have had to redirect highly qualified therapists away from serving children so they can instead manage the added overhead tasks, without commensurate reimbursement, and with fewer hours to plan for and offer services to children.

The shortages have impacted children in urban, suburban, and rural communities. For example:

- In Franklin County, an established agency shut down its EI program in June 2016 due to inadequate reimbursement rates, leaving dozens of children and families without services. Two years later, approximately half the children eligible for EI services were on a waitlist for services.
- In Monroe County, 319 children, representing 20% of County children identified as needing EI services, were on a waitlist for at least 30 days between January and July 2017. Furthermore, in the past year, two of the largest providers of EI service coordination, serving more than 400 children, stopped providing service coordination.
- In New York City in June 2017, an agency that was providing EI service coordination to 2,400 children ended its 24-year EI program because the program was not financially viable. Meanwhile, in the first few months of 2018, 15% of Black and Hispanic children in the Bronx found eligible for EI services did not receive any of their mandated services.

Provider shortages and waitlists mean children who are desperately in need of services are forced to wait during a period when initiating those services would make the biggest difference. In addition to jeopardizing access to services, these delays threaten to violate legal requirements that children receive their service plan within 45 days of being referred. If New York does not act soon to stabilize the EI system, the short- and long-term impacts on children and families could be devastating.

In order to address this crisis, we join other advocates and stakeholders across the state in urging the State to take the following steps:

- **Recommendation 1: Begin restoring reimbursement rates by increasing the current rates by at least 5% this year.** Restoring reimbursement rates is necessary to ensure that children can receive high-quality EI services at the time when intervention is most effective.
- **Recommendation 2: Increase reimbursement from private health insurance companies** by changing state law to prohibit them from denying coverage for EI claims based on lack of medical necessity documentation, lack of precertification, use of out-of-network providers, and other similar reasons for denial. Reinvest this funding into the EI program to support quality improvement efforts and recruitment and retention of high-quality professionals.
- **Recommendation 3: Conduct a cost study, with stakeholder input,** to assess and recommend changes to the methodology used to determine payment for EI evaluations, service coordination, and service provision. The cost study should consider potential changes to EI rates and reimbursement policies, including enhanced reimbursement rates for high poverty areas and areas with provider shortages; hourly vs. capitated rates for service coordination; travel time reimbursement; and reimbursement for professional development. The study should also examine ways to maximize reimbursement from private health insurance companies, including covered lives proposals.

Thank you again for providing an opportunity to examine how to improve the systems serving some of the most vulnerable children in our state.

Respectfully,

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