



Science at the heart of medicine

Children's Evaluation and
Rehabilitation Center

Rose F. Kennedy University Center for
Excellence in Developmental Disability
Education, Research and Service



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**TESTIMONY OF ROBERT MARION, MD
JOINT LEGISLATIVE HEARINGS OF THE NEW YORK STATE SENATE
AND ASSEMBLY HEALTH / MEDICAID COMMITTEES
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My name is Dr. Robert Marion, and I am the Director of the Rose F. Kennedy University Center for Excellence in Developmental Disabilities (RFK UCEDD) and its clinical program, the Children's Evaluation and Rehabilitation Center (CERC). Since its founding in 1956, CERC, like its parent institution, the Albert Einstein College of Medicine, has been located in and has served the people of the Bronx, the poorest urban county in the US. This testimony is being submitted because I am greatly concerned about the rapid change in service delivery for individuals with intellectual and developmental disabilities (IDDs) from "straight" Medicaid to Medicaid Managed Care (MMC). It has taken years to build the system of clinical services that is currently available for these individuals, and in fact, protection for New York State's most vulnerable citizens has required the inclusion of Article 16 and Article 28 within Section 364J of the New York Social Service Law. The consequences of rapid systemic changes without careful analysis might well result in a major loss of dedicated, well-trained, and experienced service providers, professionals who may never return to the care delivery system if this system is dismantled.

CERC's clients reflect the demographics of the county in which we are located. Approximately 80% are Latino and African American; many are poor, both financially and in terms of access to medical and treatment services. Since its inception, CERC has provided a broad spectrum of services for infants, children, and adolescents and about 25% of the individuals we serve are adults. These people live in our community, and come to us for treatment of autism, learning disabilities, cerebral palsy, IDDs, and other related conditions.

But CERC is much more than a clinical program serving an underserved population. One of the largest facilities of its kind in the US, CERC is a free-standing, voluntary, non-sectarian center whose services are essential components of the care available to individuals with disabilities in the New York metropolitan area; we are affiliated with and serve two major hospital systems. But in addition to providing clinical care to individuals with disabilities, our

mission includes the training of the next generations of leaders in the field of disability care and the performance of research that will improve the lives of individuals with disabilities and their families. In fulfilling this tri-fold mission, we have the distinction of having achieved the following unique federal designations:

- (1) **University Center for Excellence in Developmental Disabilities (UCEDD):** Designated and supported by the US Department of Health and Human Services' Administration on Intellectual and Developmental Disabilities (AIDD), the RFK UCEDD is one of only 67 regional UCEDDs in the US. The UCEDD conducts training, provides exemplary clinical services, furnishes technical assistance, carries out research in the field of IDD, and creates a bridge between the medical college and the community through various outreach and dissemination activities, and by direct consumer involvement.
- (2) **Intellectual and Developmental Disability Research Center (IDDRC):** Designated by the National Institutes for Health's Eunice Kennedy Shriver National Institute of Child Health and Human Development, the Rose F. Kennedy (RFK) IDDRC is one of only 15 IDDRCs in the US. Working closely with the staff of the UCEDD, researchers affiliated with the IDDRC are at the forefront of translational research efforts, working in the lab to devise solutions to questions raised at the bedside, and providing those solutions for use by clinicians. In so doing, the IDDRC aims to dissolve barriers between basic science research and clinical care, so that all can work together to reach the goal of improving the lives of individuals with IDD and other disabilities and their families.
- (3) **Leadership Education in Neurodevelopmental Disabilities (LEND) and affiliated training programs:** Funded through the Maternal and Child Health Bureau (MCHB) of the Health Resources and Services (HRSA) Agency of the US Public Health Service, CERC's LEND program is one of only 43 such programs in the US. Supporting interdisciplinary clinical training for medical and allied health professionals who care for individuals with special health care needs, CERC's LEND program offers training to some 1,000 students and professionals each year from 20 separate disciplines, including developmental-behavioral pediatrics, special care dentistry, rehab medicine, psychology, social work, physical, occupational and speech and language therapy, audiology, genetic counseling, law and advocacy, etc.

It is noteworthy that our program is one of only six centers in the United States that has all three of the above designations.

First and foremost, CERC is a much-needed clinical resource for the Bronx community and the New York metropolitan area. Each year, our professional staff provides more than 55,000 diagnostic, therapeutic and related visits to approximately 7,500 individuals with disabilities and their families. Included in this population are some 1,000 children and adults

with autism spectrum disorder. Because this population is poor and services are not plentiful, many of our clients would have no place to turn if CERC were forced to close its doors.

An immediate concern that has been brought to our attention is related to the transitioning of individuals who had in the past been exempted from enrollment in Medicaid Managed Care because they had fallen into an exempt category of persons with "MR/DD." In an effort to comply with the NYS Medicaid Redesign Team's recommendations, in August of 2012, the NYS Department of Health (DOH), in conjunction with the Office of Persons with Developmental Disabilities (OPWDD), embarked on a plan to enroll this exempted group into MMC plans unless they were specifically known to OPWDD. So, in essence, both children and adults would go from fee-for-service Medicaid or "straight Medicaid" to MMC. Letters advising families of the need to enroll their children or adult with an IDD in a MMC program were received by families in mid-August 2012 with a deadline date of enrollment in a plan by September 1, 2012. The consequence of failure to enroll such individuals would be automatic enrollment.

In August, CERC staff began to receive calls from some of the families we serve, requesting assistance in this enrollment process. In the first two weeks, nearly 40 families contacted staff members; over the first month, the number grew to 80. In essence, hundreds of individuals were affected by this change. In an attempt to assist this group, we contacted NYS DOH and were able to arrange for a six month delay for some individuals until OPWDD eligibility could be established. However, families who were unprepared to navigate government requirements were overwhelmed by the need for change. Being concerned that they would lose health care coverage, some families enrolled in a plan rather than wait for eligibility into an unknown system of care (It should be noted that due to our Article 16 and Article 28 licenses, CERC could still provide services to these families). Because no specific managed care plan information was sent to these families and no resources were put in place to answer their questions, some parents hastily chose plans based on advice from other parents. Parents who proactively enrolled in plans are now encountering changes in their coverage such as:

- Inability to obtain medications their family members had been receiving for years;
- Inability to be seen by specialists who had been following their family members for many years, and with whom a long standing relationships had been developed;
- Limitation on durable medical equipment, supplies such as catheters, diapers, gloves and nutritional food supplements, and refusals to replace or fix durable medical equipment.

As a policy consideration, the impact of this change has not yet been fully realized; however, the alterations already seen clearly jeopardize advances in health care that have taken years to achieve. Having to rely on MMC with artificial limits, caps on services, incentives to restrict services, and staff with limited time to communicate and little or no experience or training in caring for individuals with special needs will make it difficult for individuals with IDDs to receive the following:

- Specialized medical care necessary for diagnosis, habilitation and rehabilitation. This includes physical and rehabilitation medicine, otolaryngology, ophthalmologic, neurologic, psychiatric and other specialty services. These services will remain available as long as the Article 16 carve out remains in place. Once this carve out is lost, ability to access these services may be lost; the consequences of this may be dire.
- The special needs of children with IDD's must be addressed and discussed, since the status of care for children within either the MMC plans or the "DISCO's" remains both uncertain and ambiguous. Clinical and mental health services for individuals with special needs are preventive and reduce unnecessary trips for emergency facilities for both medical and mental health interventions. These interventions along with family interventions keep people, both children and adults, in their homes and out of institutional settings.
- Special care dentistry, an essential service that is already in limited supply in NYS. CERC's Special Care Dentistry service utilizes intravenous (IV) sedation, eliminating the need for general anesthesia (which, itself, necessitates that the individual be admitted to a hospital and taken to an operating room for routine dental care). IV sedation is both cost effective and less invasive, reducing hospitalizations and operating room costs and freeing up operating rooms for other medical procedures.
- Durable specialized medical equipment for severely physically disabled Medicaid recipients, such as, wheelchairs (including wheelchair repair), shower equipment, seating systems, braces etc. continues to require substantial documentation that is extremely time-consuming, resulting in fewer service providers choosing to work with the population. In addition, as a result of the paucity of Medicaid reimbursement, many vendors are unwilling to provide equipment for persons with severe physical and IDD's.
- Disposable supplies, such as bladder catheters, adult diapers, irrigation trays, and other equipment necessary for maintaining health must be adequate to meet the individual needs of the person so that they can live in the community and function as independently as possible.

On a positive note, as of January 1, 2013 transportation for non-emergent medical services was taken over by NYS DOH, rather than being left to MMC plans and is now provided by LogistiCare. Once initial transportation quirks are worked out, this change will help solve some problems with MMC plans and transportation to our clinic and out of network services which has plagued us for years. However, it remains vitally important that any treating physician whether part of an MMC or not, should be allowed to authorize ambulette and other forms of transportation services to bring individuals to and from appointments who otherwise would not be able to travel due to their IDD's.

The change to MMC has already had an impact on the precarious service delivery system to this population. In an editorial entitled "At Special Olympics, a Race for Better Health" (Sept. 25) the *New York Times* noted the "shocking inadequacies of health care..." that already exists for this population. With the institution of MMC, coupled with other changes that appear to be

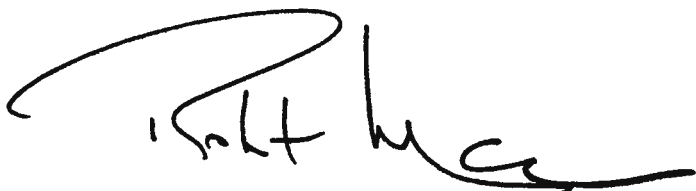
in the planning stages, it is imperative that both the Article 16 and 28 carve-outs remain as viable entities. If these carve-outs were to vanish, we fear that a crisis in health care delivery to individuals with IDD and other disabilities will be on the horizon. In order to avoid this looming crisis, we urge that:

- **Enrollment of individuals with special needs and IDD be postponed until DISCOs or special needs plans are in place and careful consideration of the impact on services can be fully addressed. The Article 16 and 28 carve-outs are maintained in their current format so as to assure quality and continuity of clinical care. Without continuation of the carve out, CERC will be in danger of losing all of its federal training and research funds and will have to close its doors and there will be no one else in the region to provide the essential services that it now provides.**
- **In the future, individuals with IDD and their families should be given specific written information that is understandable and in their dominant language so that they can make informed decisions in a reasonable amount of time regarding health care coverage and plans.**

Finally one last comment; neither fee for service nor MMC will work unless there is sufficient funding that is based on actual costs. Funding that is substantially below cost will doom any service delivery system.

Thank you for your interest and concern regarding this very important matter. The CERC staff and I would be happy to answer any questions or provide additional information.

Respectfully submitted,

A handwritten signature in black ink, appearing to read "Robert Marion", with a large, sweeping flourish at the end.

**Robert Marion, MD
Director, RFK UCEDD and CERC**