Medically Fragile Children Work Group Report

Submitted by the Commissioners of the
Department of Health and
Office for People with Developmental Disabilities to the
Governor and the Legislature

February 2013

Medically Fragile Children (MFC)
Work Group Report

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Executive Summary

The New York State 2012-13 Enacted Budget (Chapter 56 of the Laws of 2012, Part D, Section 34-b Appendix A) directed the Commissioners of the Department of Health (DOH) and Office for People with Developmental Disabilities (OPWDD) to convene a Work Group on Medicaid payments for services to Medically Fragile Children (MCF) to make recommendations on:

- the adequacy and viability of Medicaid payment rates to certain pediatric providers that serve MFC;
- appropriate models for care coordination of MFC; and
- the transition of the pediatric nursing home population and benefit to managed care, including home care agencies affiliated with pediatric nursing homes and diagnostic and treatment centers (i.e., clinics) which primarily serve MFC.

The members of the MFC Work Group are comprised of stakeholders, providers that specialize in the care of pediatric patients, including nursing homes (NHs), clinics and hospitals that primarily serve MFC, Care at Home providers; representatives of families of MFC; and other MFC experts. See Appendix B for a list of the MFC Work Group members.

In accordance with the statutory directives of the MFC Work Group, this Report, which includes the findings and recommendations of the Work Group, is being submitted by the Commissioners of DOH and OPWDD to the Governor, and the Chairs of the Health and Fiscal Committees of the Legislature.

As described in more detail later in this Report there are almost 13,000 MFC who received more than $900 million in annual Medicaid health services. Those Medicaid services are now reimbursed through a combination of fee-for-service and per member per month (i.e., managed care) payments.

DOH has established a goal of having virtually all Medicaid enrollees, including MFC, served in care management by April 2016. This initiative, deemed "*Care Management for All*," began in State Fiscal Year (SFY) 2011-2012 as a Medicaid Redesign Team (MRT) proposal.

Care Management for All will improve benefit coordination, quality of care, and patient outcomes over the full range of health care, including mental health, substance abuse, developmental disability, and physical health care services. It will also redirect almost all Medicaid spending in the state from fee-for-service, under which service providers bill directly to the state, to care management, under which a Managed Care Organization, of one type or another, is paid a capitated rate by the state and is then responsible for managing patient care and reimbursing service providers

The following recommendations of the Work Group reflect a course of action to ensure the special and complex needs of Medicaid's medically fragile children are addressed as they transition to Managed Care over the next few years. Importantly, the recommendations ensure continuity of care and facilitate the continuation of the direct participation and advocacy of the members of the Work Group, other pediatric providers, stakeholders, Managed Care Plans ("Plans"), and DOH and OPWDD.

Recommendation #1: Utilize the Health Home model to provide care coordination for MFC, prioritizing assignment to children who are eligible for Health Home services but are currently not receiving care coordination.

Recommendation #2: Allow CAH I/ II, III, IV and VI children that are enrolled in Managed Care to retain their waiver services until such time as the waivers end and are transitioned to Managed Care.

Recommendation #3: Establish an Advisory/Implementation Committee comprised of Managed Care Plan representatives, providers, consumers and DOH and OPWDD staff, to ensure smooth transition of MFC to Managed Care.

Recommendation #4: Establish Managed Care premiums that are all inclusive and provide sufficient resources to meet the complex needs and range of services required to care for MFC.

Recommendation #5: DOH and the pediatric nursing homes work together to develop a new pricing methodology for the operating component of the rate that will provide a rational benchmark rate for the transition to Managed Care.

Recommendation #6: Work with nursing homes to establish new pediatric ventilator bed capacity, including long term capacity, aimed at repatriating out-of-state MFC patients.

Background

Defining Medically Fragile Children (MFC)

The Work Group agreed that to make meaningful recommendations and effectively communicate those recommendations to Managed Care Plans, policymakers, advocates, DOH and OPWDD, it would be important to define a medically fragile child. The Group agreed that a comprehensive definition of a MFC should consider diagnoses and the type of services received from programs and providers (e.g., pediatric nursing home, children's clinic or hospital, or community based Medicaid (MA) waiver services). In addition, to facilitate the ability to monitor patterns of care to ensure and measure quality and cost effectiveness, the definition should be applicable to the Medicaid database (eMedNY). After lengthy discussion and data analysis, the Work Group developed the following definition.

A medically fragile child is defined as an individual who is under 21 years of age and has a chronic debilitating condition or conditions*, who may or may not be hospitalized or institutionalized, and is:

- technologically-dependent for life or health-sustaining functions, and/or
- requires a complex medication regimen or medical interventions to maintain or to improve their health status, and/or
- in need of ongoing assessment or intervention to prevent serious deterioration of their health status or medical complications that place their life, health or development at risk.

*Chronic debilitating medical conditions include, but are not limited to, bronchopulmonary dysplasia, cerebral palsy, congenital heart disease, microcephaly, and muscular dystrophy.

To try to reasonably apply the MFC definition to the Medicaid claims database, CAH I/II, III, IV and VI waiver participants were presumed to be MFC (i.e., children in CAH meet the MFC definition). However, to identify individuals receiving different types of services through many different programs and providers (e.g., children's hospitals, pediatric nursing homes, clinics, Certified Home Health Agencies, private duty nursing) the group developed a list of diagnoses (See Appendix C) to use as a tool to help link the MFC definition to the information provided on claims. Note that not every child that has one of the diagnoses listed in Appendix C will meet the definition of an MFC and children with a combination of these diagnoses and perhaps other diagnoses may meet the MFC definition. Additionally, children receiving Certified Health Home Agency (CHHA), private duty nursing (PDN) or per member per month (PMPM) services in excess of $10,000 were included in the claims identified to help link the MFC definition to claims data.

Examples of MFC Children

Below are several examples of children receiving Medicaid services that meet the Work Group's definition of a MFC.

Example 1: An Adolescent Enrolled in Care at Home II Waiver on a Ventilator: This adolescent patient has encephalopathy, feeding difficulties, convulsions, delayed milestones, and respiratory abnormalities. The total annual healthcare costs for this patient were $175,701 of which $166,850 were for home nursing services, home care services and supplies, use of ambulance services for transportation, and 12 outpatient visits requiring the use of ambulette services for transportation.

Example 2: A Child in a Pediatric Nursing Home: This child has infantile cerebral palsy and requires multiple mechanical interventions including tracheostomy and ventilator care. The patient resides at a pediatric nursing home and had three Emergency Department visits during the calendar year. The 2011 costs to meet the healthcare needs of this patient was $228,537 of which $225,421 was attributable to the nursing home (365 days) and $3,116 was for pharmacy and other costs associated with ventilator care and transportation.

Example 3: An Adolescent in a Pediatric Hospital: This adolescent patient has obstructive hydrocephalus, congenital quadriplegia, infantile cerebral palsy, epilepsy, hip dislocation and thigh injury, and asthma. The patient received care at multiple facilities, including a general hospital and children's hospital. Multiple orthopedic surgical procedures were required during the calendar year The patient's healthcare costs for 2011 were $172,233 of which $147,730 were for hospital, clinic, rehabilitation, assessment and care coordination.

Medicaid Spending for MFC

These children have complex healthcare needs and often multiple morbidities that require them to rely on multiple providers to deliver a range of services covered by a mix of public and private payers (e.g., Medicaid, Medicare, third party health insurance etc.) depending on patient and/or family eligibility. Medical services, including some care coordination, are delivered to MFC patients through several types of Medicaid programs and providers that may be reimbursed through fee-for-service or Per Member Per Month (PMPM) payments.

Based upon the Work Group's MFC definition, the Medicaid program currently provides more than $900 million of critical health care services to almost 13,000 MFC recipients. The healthcare needs for these children is significantly more resource intensive and costly than that of other Medicaid children—$70,524 Per Member Per Year (PMPY) for MFC compared to $3,588 PMPY for all Medicaid Children under age 21.

Approximately 55 percent of the MFC children already receive care through a Managed Care Plan. MFC represent just 0.6 percent of the total number of Medicaid children under the age of 21, and 12 percent of total Medicaid spending for children.

Medicaid Spending for Children 55% of MFC Are Already Enrolled in Managed Care							
Payer Type	**Number of Medicaid Children Under Age 21**	**Percent Share of Children Under Age 21**	**Number of MFC Recipients**	**Percent Share of MFC Children**	**2011 Medicaid Spending for MFC Children ($ in Millions)**	**Percent of Medicaid Spending for MFC by Payer Type**	**Annual Spending Per MFC Recipient by Payer Type**
Fee-for-service (FFS)	334,749	15%	5,855	45%	$776.5	86%	$132,622
Managed Care	1,900,618	85%	7,013	55%	$131.0	14%	$18,680
Total	2,235,367	100%	12,868	100%	$907.5	100%	$70,524

The table below describes Medicaid spending for MFC by program and provider type and allocates that spending between fee-for-service and per member per month reimbursement. Following the table is a brief summary of the current Medicaid programs and types of providers that care for the Medicaid MFC population. Many of the programs are community based and thus focus on providing at home care for children with long term special care needs.

2011 MFC Medicaid Spending by Program/Provider Type				
Program/Provider Type	**Number of Providers[1)]**	**Number of MFC Children[2)]**	**Total Medicaid Spending ($ in Millions)**	**Annual Cost Per MFC Children**
Medicaid FFS				
Care at Home I/II	15	899	$73.9	$82,202
Care at Home III, IV & VI	19	559	$28.8	$51,521
Home and Community Based Services	27	406	$39.5	$97,291
Pediatric Nursing Homes	9	507	$142.3	$280,671
Pediatric Hospital	1	182	$44.4	$243,956
Specialty Hospital	1	21	$7.3	$347,619
Intermediate Care Facilities	18	57	$13.4	$235,088
Children Clinics	2	395	$20.0	$50,633
Long Term Home Health Care Program (LTHHCP)	10	582	$32.7	$56,186
Certified Home Health Agencies (CHHAs)[3)]	100	851	$155.7	$182,961
Private Duty Nursing (PDN)[3)]	70	44	$7.4	$168,182
Other MFC[3)] Children	N/A	1,352	$211	$156,065
Total Fee-for-Service (FFS)	**N/A**	**5,855**	**$776.5**	**$132,622**
Total Managed Care Spending [4)]	**N/A**	**7,013**	**$131.0**	**$18,680**
Total MFC Spending	**N/A**	**12,868**	**$907.5**	**$70,524**

1) # of Providers who served MFC in calendar year 2011
2) Children are counted mutually exclusively based on hierarchy of program presented above
3) Children with MFC Diagnoses and PMPM costs of $10,000 or more
4) Please see Appendix D for more detail on the components of total Managed Care Spending for MFC

- Average annual fee-for-service Medicaid spending for the 5,855 children that met the Workgroup's MFC definition was $776.5 million, $132,622 per recipient.
- Average annual spending ranged from $347,619 for children in pediatric specialty hospitals to $50,633 for MFC seen in children's clinics.
- Children meeting the Workgroup's MFC criteria in institutions (nursing homes, pediatric and specialty hospitals, and Intermediate Care Facilities) comprised 13 percent of the population and 27 percent of the spending compared to children enrolled in Medicaid waivers who comprised 42 percent of the children and 23 percent of the spending. The remaining 45 percent of MFC are served by LTHHCP, CHHAs, PDN and other and account for 50 percent of the spending.

The following table provides a regional comparison of Medicaid spending by program category.

2011 Total Fee-for-Service Spending for MFC by NYC and Rest of State (ROS)[1] ($ in Millions)			
Programs	**NYC Medicaid Spending**	**ROS Spending**	**Statewide Total Spending**
Care at Home I/II	$25.0	$48.9	$73.9
Care at Home III,IV& VI	3.9	24.9	28.8
Home & Community Based Services	11.2	28.3	39.5
Pediatric Nursing Homes	104.5	37.8	142.3
Pediatric Hospital	33.0	11.5	44.0
Specialty Hospital	7.1	0.2	7.3
Intermediate Care Facilities	7.4	6.0	13.4
Children's Clinics	6.3	13.7	20.0
Long Term Home Health Care Program (LTHHCP)	29.7	3.0	32.7
Certified Home Health Agencies (CHHAs) [2]	103.8	51.9	155.7
Private Duty Nursing (PDN) [2]	2.5	4.9	7.4
Other MFC Children [2]	122.0	89.0	211.0
Total	**$456.2**	**$320.3**	**$776.5**

1) Provides Medicaid spending by program category based on the recipients county of residence
2) Children with MFC Diagnoses and PMPM costs of $10,000 or more

- The majority of Medicaid spending for MFC was attributable to children in NYC (59 percent).
- MFC institutional spending for children in NYC was $152 million (73 percent) compared to children in the rest of the state (ROS) who accounted for $56 million (27 percent).
- Waiver spending for children in NYC was $70 million (40 percent) compared to children in the ROS who accounted for $105 million (60 percent).
- MFC PDN and CHHA spending for children in NYC was $106 million (65 percent) compared to $57 million (35 percent) children in the ROS.

The following table shows per recipient annual spending by program category and by region of the State.

Fee-for-Service, Per Person Per Year (PPPY) for MFC Recipients by Region (NYC or ROS) of Residence					
Program	**NYC Recipients**	**NYC Medicaid Spending (PPPY)**	**Rest of State Recipients**	**Rest of State Medicaid Spending (PPPY)**	**Statewide Medicaid Spending (PPPY)**
Care at Home I/II	242	$103,334	657	$74,391	$82,182
Care at Home III,IV,&VI	62	63,579	497	50,109	51,603
Home & Community Based Services	83	134,630	323	87,683	97,281
Pediatric Nursing Homes	346	302,066	161	234,679	280,667
Pediatric Hospital	127	259,726	55	208,305	244,187
Specialty Hospital	20	356,431	1	159,141	347,037
Intermediate Care Facilities	28	263,797	29	206,347	234,568
Children's Clinics	110	57,422	285	48,028	50,644
Long Term Home Health Care Program (LTHHCP)	510	58,156	72	41,807	56,133
Certified Home Health Agencies (CHHAs)	561	185,037	290	178,900	182,946
Private Duty Nursing (PDN)	15	168,086	29	169,373	168,934
Other MFC Children	784	155,344	568	157,192	156,121
Total	**2,888**	**$157,975**	**2,967**	**$107,941**	**$132,620**

- Overall, the PPPY MFC FFS Medicaid spending was 46 percent higher for children in New York City (NYC) compared to ROS.
- PPPY spending for a few categories was relatively consistent for children in NYC and the ROS for PDN (-1 percent) and CHHA (3 percent) and 'Other MFC' (-1 percent).
- PPPY spending for several categories varied significantly for children in NYC and the ROS, particularly for children in MA waivers: Office of Persons with Developmental Disabilities Comprehensive Waiver (54 percent), Care at Home I/II (39 percent), and the Long Term Home Health Care Program (39 percent).

Programs that Provide Care for Medically Fragile Children

Home and Community Based Services (HCBS) 1915(c) Medicaid Waiver Programs provide specialized medical and nonmedical services and supports necessary to allow participants to live and receive care in the community as an alternative to a nursing home or other institutional setting. A waiver is "an exception to certain Federal Medicaid statutory requirements that allow a State to furnish an array of home and community based services that promote community living for Medicaid beneficiaries and thereby avoid institutionalization". Waiver services complement and/or supplement the services available through the Medicaid State Plan, other Federal, State and local public programs as well as the supports that families and communities provide. Services provided through 1915(c) waivers are eligible for Federal Participation Revenue.

The Care at Home (CAH) I/II Program serves children under age 18 determined physically disabled based on Social Security Administration criteria, and who require either a nursing facility or hospital level of care. Children from Medicaid eligible families and those ineligible for Medicaid due to parents' excess income and/or resources but eligible based on their own

resources, when their parents' income and/or resources are not counted, may participate in the waiver.

The purpose of the waiver is to avoid unnecessary institutionalization of eligible children by providing access to appropriate community based care. In addition to Medicaid State Plan services, participants have access to service coordination, home/vehicle modifications, respite, and five pediatric palliative care services: family palliative care education, pain and symptom management, bereavement services, massage therapy, and expressive therapies.

An important element of the CAH I/II Program is case management. This service assists participants in gaining access to needed waiver, State Plan services, and other services. Service delivery is arranged by the CAH I/II case manager in accordance with the participant's plan of care developed in conjunction with the child's family/legal guardian and physician. The plan of care identifies waiver and State Plan services necessary to maintain the participant safely in the home community that, in the aggregate for all CAH I/II waiver participants, are cost neutral compared to institutional care. All CAH I/II services are delivered by DOH enrolled Medicaid providers; the exception being that home/vehicle modifications are delivered through contractors chosen by the family.

CAH I/II services are reimbursed through Medicaid fee-for-service, regardless of whether the child is enrolled in a Managed Care Plan. The total annual costs, on an aggregate Statewide basis, must be less than the cost of institutionalization.

DOH administers and provides oversight of the waiver program. The 62 Local Departments of Social Services (LDSS), charged with implementing the program, are responsible for the daily operations and administrative functions of the CAH I/II waiver.

The Care at Home (CAH) III, IV, and VI Programs are operated by the New York State Office for People With Developmental Disabilities (OPWDD) under three Medicaid waivers to provide services to children under the age of 18, with severe developmental disabilities and complex medical conditions, who are living at home with their families. The child must meet Intermediate Care Facility/Developmental Disability (ICF/DD) Level of Care and medical screening criteria and the total cost of care under this waiver must be less than in an ICF/DD. The waiver includes case management, respite care, environmental modifications and assistive technologies.

Case management is also an important element of the CAH III, IV and VI program. Case management activities are performed by a case manager and include assisting patients in gaining access to needed waiver and other State Plan services, as well as medical, social, educational and other services (regardless of the funding source for the services). Case management agencies are enrolled Medicaid providers. Additionally, DOH has on-going oversight of OPWDD CAH case management.

The case manager is responsible for working alongside the family to develop a service plan for the child. The case manager works with all involved professionals to ensure that services are in place to meet a child's particular needs and treatment goals. This level of involvement is ongoing and requires at least one face-to-face visit with the child each month. The service plan is reviewed every six months, but is regularly revised whenever a need or change occurs in the child's condition or situation.

CAH III, IV and VI services provided to children not enrolled in a Managed Care Plan are reimbursed through Medicaid fee-for-service rates and total annual costs must be less than costs of an intermediate care facility.

To be eligible for CAH III, IV, VI, the child must not be eligible for Medicaid when parents' income/resources are counted, and must be eligible for Medicaid when parents' income and resources are not counted. Currently, these three CAH waivers combined serve up to 600 total children. Effective April 2013 (pending Federal approval), the existing OPWDD Medicaid waivers will be consolidated into a single waiver which will continue to serve OPWDD recipients under age 18 with no changes to the existing service model or policies.

The OPWDD Comprehensive Home and Community Based Services (HCBS) Waiver enables OPWDD to provide home and community based supports to individuals who would otherwise require an institutional level of care. The waiver is available to children and adults with a developmental disability who meet Intermediate Care Facility/Developmental Disability (ICF/DD) Level of Care criteria. A subset of enrollees can be described as medically frail. This waiver includes community, day and residential habilitation, along with respite care, environmental modifications, assistive technologies, family education, training, community habilitation and other supports. Case Management is provided to waiver participants in a non-medical model through Medicaid Service Coordination (MSC) under the State Plan. For less intensive case management, Plan of Care Support Services (PCSS) is available under the HCBS waiver.

The Long Term Home Health Care Program (LTHHCP) is also known as the Lombardi or Nursing Home Without Walls program. First authorized in 1983, the program offers a coordinated plan of care and services for individuals of all ages who would otherwise be medically eligible for placement in a hospital or residential health care facility. Waiver participants must have assessed needs that can be met safely at home through a plan of care. Medicaid costs are reimbursed through fee-for-service reimbursement methodology and total costs of care must be less than 75 percent of the costs of skilled nursing facility (case-by-case exceptions may allow costs to be no more than 100% of the costs of skilled nursing facility). LTHHCP services may be provided in the person's home, an adult care facility (other than a shelter for adults), or in the home of a responsible adult.

NYSDOH authorizes LTHHCP agencies pursuant to a formal certificate of need process, and monitors the agencies by standard periodic inspections to assure adherence to quality of care standards. LTHHCP agencies provide case management, and are responsible for providing or arranging necessary State Plan home care (personal care, home health aide, nursing, physical therapy, occupational therapy and speech pathology), and authorized waiver services. Children enrolled in the LTHHCP principally receive assistive technology, environmental modifications, medical social services, respiratory therapy, and respite care.

Providers that Care for MFC

Children's Hospitals

Blythedale Children's Hospital is New York State's only independent specialty children's hospital and is located downstate in Valhalla, New York. The hospital has 86 beds and provides medical/surgical care, physical medicine and rehabilitation, traumatic brain injury and coma recovery care. Clinical services include medical, nursing, physical therapy, occupational therapy, speech and feeding therapy and supportive services (i.e., laboratory, radiology, social

work and child life). Blythedale services are reimbursed through statutory fee-for-service methodology which is currently based upon 2007 base year costs adjusted for inflation.

Specialty Hospital at Terence Cardinal Cooke Health Care Center (TCCHCC)
The Specialty Hospital at TCCHCC has provided services to medically fragile children and adults since its establishment in 1978. The facility was developed to allow appropriate MFC to remain in a stable medical home while they age out of pediatric facilities. The Specialty Hospital works aggressively in the repatriation of out-of-state MFCs and serves a total 50 MFC and MFA (Medically Fragile Adults). The Specialty Hospital provides comprehensive 24 hour 7 day a week medical and nursing care and specialty services including neurology, physiatry, ophthalmology and dental care. In addition, the Hospital also offers rehabilitative services, and has respiratory/ventilator capabilities and provides supportive services such as laboratory and radiology to the MFC as needed per their individual care plan. The patient and the family/guardian are central to the care planning and the psychological needs of both the patient and the family are addressed by social work and psychiatric care staff. TCCHCC has partnered with the Mount Sinai Hospital (MSH) data system, EPIC, to facilitate the integration of care in an acute care setting.

Children's Clinics
There are two clinics in the State that primarily serve children – Blythedale Children's Clinic and the Children's Rehabilitation Center (CRC). Both clinics are located downstate and provide medical and rehabilitative services to children with developmental disabilities, orthopedic impairments and other complex medical diagnoses.

Certain clinic services provided by Blythedale have been carved out of Managed Care due to the unusual and special nature of the services provided (including a prolonged average length of stay of over 100 days per patient) and the Plans historic unfamiliarity with these types of special services. Thus, Blythedale clinic services are currently reimbursed through statutory fee-for-service rates based on 2007 costs. Current statute contemplates data and information sharing between Blythedale and the Department to assist in the development of ambulatory patient groups (APGs) rates. To provide flexibility in the development of alternative rate methodologies that are appropriate to the services provided by Blythedale (as well as other clinics, including CRC) the 2013-14 Executive Budget amends the current statute to allow such methodologies to be developed pursuant to regulation.

Clinic services provided by CRC for children not enrolled in a Managed Care Plan are reimbursed through fee-for-service rates based on APG rates that includes a 20 percent payment enhancement that is triggered by billing the P3 modifier (severe systemic disease) when appropriate. CRC services provided to children enrolled in a Plan were reimbursed under a negotiated contract at CRC's fee-for-service APG rate. However, earlier this year, Hudson Health Plan terminated its contract with CRC. This resulted in an immediate migration of children that were being served by CRC and enrolled in Hudson Health Plan to Blythedale – the services of which are carved out of Managed Care and reimbursed at Blythedale's fee-for-service rate. The disparity in the reimbursement methodology between Blythedale and CRC provided an incentive for Hudson Health Plan to reduce its costs and that resulted in the disruption of services to children enrolled in Hudson Health Plan.

To address this issue, under the authority provided in the statute establishing the Medically Fragile Children (MFC) Work Group (see Appendix A), effective July 18, 2012, the Department notified the Managed Care Plans that all services provided to children that are members of Plans being served by CRC will be exempt for Medicaid Managed Care recipients and will be

billed separately at CRC's fee-for-service rate. Both the Plans and CRC were also notified that the exemption from Plan was being provided on a temporary basis until such time as the MFC Work Group makes its recommendations. Recommendation #4, discussed in more detail below, addresses this issue by recommending all services be included in Managed Care premiums with a transition period that requires the Plans pay the current fee-for-service rates for Clinics for a period of time and options to be explored to address the disparity in pediatric clinic rates.

Clinics Licensed by OPWDD (Article 16 Clinics)
OPWDD licensed clinics, including the Developmental Disability Clinic (DDC) at Terence Cardinal Cooke Health Care Center, deliver diagnostic, evaluation, and long-term clinical support services to children and adults with developmental disabilities. Although not focused primarily or exclusively on medically frail children, Article 16 clinics are an important part of the care network for medically frail children in many parts of the State –especially for occupational therapy, physical therapy, speech therapy, nutrition, and psychological services. Further, many Article 16 clinics are also jointly-licensed as Article 28 (DOH-licensed) clinics. Such jointly-licensed facilities are able to provide comprehensive medical and therapeutic services under a single roof and serve important role in the delivery of services to Medically Fragile Children with cerebral palsy, spina bifida, epilepsy and other severe developmental impairments. These clinics also serve adults and children with developmental disabilities who have less severe physical health needs.

Pediatric Nursing Homes
There are nine pediatric nursing facilities (5 standalone pediatric facilities and 4 units that operate within geriatric nursing homes) currently operating a total of 501 beds in New York State Two of these facilities are located in the Capital Region, one is located in the Buffalo area, and the remaining facilities are located downstate. Pediatric nursing homes are those that care solely for pediatric patients that require extensive nursing, medical, psychological and counseling support services. Please see recommendation #5 for detailed information regarding the current Medicaid reimbursement methodology for pediatric nursing homes.

Intermediate Care Facilities (ICF)
An ICF is operated under the Federal part 483 regulatory requirements which prescribe comprehensive service delivery. Services delivered within the ICF/DD are "bundled", meaning that all individuals must be assessed annually regarding their needs in each of the required clinical domains and care plans must be developed to ensure that the individual is provided active treatment to address the identified needs.

These residential facilities are designed for those individuals whose disabilities limit them from living independently. Services may be provided in an institutional or a community setting. For the most part, Intermediate Care Facility/Developmental Disability (ICF/DDs) serve individuals who are unable to care for their own basic needs, require heightened supervision and the structure, support and resources that define this program type. ICF/DDs provide 24-hour staffing supports for individuals with specific adaptive, medical and/or behavioral needs and includes intensive clinical and direct-care services, professionally developed and supervised activities (day services) and a variety of therapies (e.g., physical, occupational or speech) as required by the individual's needs.

Certified Home Health Agencies (CHHAs)
Certified Home Health Agencies (CHHAs) are public, not-for-profit or proprietary, home care agencies that have a valid certificate of approval issued pursuant to the provisions of Article 36

of the Public Health Law. A CHHA is required to provide nursing, home health aide, medical supplies, equipment and at least one additional service to individuals who need intermediate and skilled health care.

Specifically, CHHA agencies provide nursing and home health aide services that include health care tasks, personal hygiene services, housekeeping tasks essential to the patient's health, and other related supportive services. They may also provide long-term nursing and home health aide services, help patients determine the level of services they need, and can either provide or arrange for other services, including physical, occupational, and speech therapy, medical supplies and equipment, and social worker and nutrition services.

All CHHA services must be prescribed by a physician in accordance with a patient's plan of treatment. CHHA services may be reimbursed by Medicare, Medicaid, private payment, and some health insurers.

Effective May 1, 2012 the CHHA fee-for-service rate setting methodology reflects a 60-day, case mix adjusted episodic pricing methodology. Children under 18 years of age and CHHA services provided to a special needs population of medically complex and fragile children, adolescents and young disabled adults by a CHHA operating under a pilot program approved by the Department are exempt from the Episodic Pricing Methodology and remain subject to the cost-based per unit of service rate methodology in effect prior to May 1, 2012.

Private Duty Nursing (PDN)
Under the Medicaid Program, medically necessary nursing services may be provided to eligible individuals in their homes through a private duty nurse. All nursing services must be in accordance with, and conform to, the ordering physician's treatment plan and requires prior approval from the central Albany office (Office of Health Insurance Program Operations, Medical Prior Approval Unit) or by contacting Westchester County DSS for those beneficiaries residing in Westchester County. PDN is approved when the medical needs of the patient require an LPN or RN level of care in duration and frequency exceeding what home health agency nurses provide. The medical needs range from feeding tubes to tracheostomies to ventilators to injections and infusions. PDN assists families and caregivers in keeping the beneficiary placed in the home versus a long term care facility.

PDN is billed to Medicaid by either independent nurses or nursing agencies and reimbursed in accordance with regulations (18 NYCRR 505.8(g)), not to exceed established regional maximum rates. Under public health law section 3614(3)(a) providers caring for children receive a 30 percent rate add-on.

Timeline for Transitioning MFC to Managed Care

DOH has established a goal of having virtually all Medicaid enrollees, including MFC, served in care management by April 2016. This initiative, deemed "*Care Management for All*," began in State Fiscal Year (SFY) 2011-2012 as a Medicaid Redesign Team (MRT) proposal. In addition to being a core objective of the MRT, Care Management for All supports the Affordable Care Act Triple Aim: improving care, improving health, and reducing per capita costs.

Care Management for All will improve benefit coordination, quality of care, and patient outcomes over the full range of health care, including mental health, substance abuse, developmental disability, and physical health care services. It will also redirect almost all Medicaid spending in the state from fee-for-service, under which service providers bill directly to the state, to care

management, under which a Managed Care Organization, of one type or another, is paid a capitated rate by the state and is then responsible for managing patient care and reimbursing service providers.

As of April 1, 2012, nearly four million of the five million NYS residents enrolled in Medicaid were already in care management, with, however, a significant portion of the benefits for those persons remaining outside the care management benefit package. Over the next four years, the bulk of the excluded benefits and patient populations will move into care management on a predetermined schedule.

This transition to Care Management for All will include enrolling the MFC population and the benefits they receive in Managed Care. The following table highlights the segments of the predetermined schedule for populations which encompass MFC. For example, the non-dual eligible nursing home population is scheduled to begin moving to managed care beginning in October 2013. This population includes MFC residing in pediatric nursing homes.

Time Line for Transition of Medically Fragile Children to Managed Care	
Population/Benefit	**Date**
Waiver "look-alike" children which are not enrolled in a waiver, but have the same medical needs and care	9/1/12
LTHHCP	4/1/13
Nursing Home Population (non-duals)	10/1/13
Nursing Home Population (duals)	1/1/15
Agency Placed Foster Care/B2H	4/1/15
HCBS CAH I/ II Waiver	4/1/16
HCBS CAH III, IV and VI The transition to Managed Care will occur after the 3 CAH waivers (III, IV and VI) are consolidated into one standard CAH waiver April 1, 2013 (pending Federal approval) and the larger comprehensive HCBS waiver has fully transitioned to Managed Care which will not occur for several years. Pending CMS approval, the first care management Plans that are approved to operate under the People First waiver are expected to begin enrollment in January 2014 (initial phase will be voluntary enrollment). A larger statewide roll-out of mandatory managed care plans for this population will begin to occur in 2015 as capacity is established through new Plans being approved to operate through the People First Waiver on a regional basis.	No Earlier than April 2015
Note: As the Medicaid Managed Care (MMC) program is presently constructed, only non-dual children can move into MMC and will be moving to Mainstream MMC (not Managed Long Term Care). CHHA and personal care services are already an "in-plan" benefit for MMC enrollees. They are covered fee-for-service for all other persons (including waiver enrollees that have not voluntarily enrolled in managed care plans).	

Work Group Recommendations

The MFC Work Group met on four occasions (July 19, 2012, August 2, 2012, August 13, 2012 and September 20, 2012). The presentations which guided the discussions at those meetings are posted on the Department's website (http://www.health.ny.gov/health_care/medicaid/redesign/). At the September 20, 2012 meeting, the Work Group discussed the possible recommendations included in that meeting's presentation and following comments and further discussion, the Work Group has developed the following recommendations.

Care Coordination for MFC (Recommendations #1 and #2)

MFC have complex health care needs that require individualized care planning across multiple sectors of the health care system and community. Currently, MFC children may receive care management reimbursed and provided for under the CAH waiver programs, or more informal care coordination that may be provided by pediatric nursing homes, children's clinics or hospitals, and other care providers for which there is no direct reimbursement. In addition, children now enrolled in Managed Care may receive some care coordination, but it may not be as extensive as required given the needs of the MFC population. Another avenue for care coordination for MFC is through Health Homes, an important program in the MRT Care Management for All initiative.

All of this naturally emphasizes the need to ensure that as MFC transition to Managed Care the types of care coordination required are accessible and uniformly available to MFC. In addition, to ensure the continuity of care for MFC, it will be important to maintain the level of service coordination that is now provided and continue to directly involve the family and service providers. In accordance with these goals and objectives, the MFC Work Group developed Recommendations #1 and #2.

Health Homes

The Federal Affordable Care Act enacted on March 23, 2010 provided states with the option to provide Health Homes for members with chronic conditions under their Medicaid (MA) State Plan. In November 2010, the Centers for Medicare and Medicaid Services (CMS) notified State Health Officials and Medicaid Directors of the opportunity to elect the Health Home option via a State Plan Amendment (SPA).

New York State decided to adopt the option of Health Home care coordination model for high cost/high need MA enrollees with two or more chronic conditions, HIV/AIDS (single chronic condition at risk for another), or a serious, persistent mental illness. NYSDOH, in collaboration with the Commissioners of the Office of Mental Health (OMH) and Office of Alcohol and Substance Abuse Services (OASAS), developed the Health Home Program and submitted a series of three State Plan Amendments (SPAs) to be phased in statewide by county. On February 3, 2012 CMS approved New York State's first Health Home SPA for Individuals with Chronic Conditions, Phase One of the Health Home Program. On December 4, 2012 CMS approved two additional Health Home SPAs for Phase Two and Phase Three. The combined approval of these three SPAs allows for statewide implementation of the Health Home Program. Phase One Health Homes have been operational since early summer 2012, Member assignment has begun in Phase Two counties and Phase Three counties are executing contacts and member assignment will begin once contracts are executed.

The Health Homes SPA requests submitted to date were not age-specific and Health Home services are available to all categorically eligible Medicaid members, however, program rollout thus far has not actively prioritized children and adolescents aged 0 through 20 years, (with the exception of children with HIV/AIDS) for enrollment into Health Homes. As children have unique health care issues that should be addressed comprehensively through age and developmentally appropriate services by qualified providers, the DOH convened an interagency team to develop programmatic recommendations for Health Homes to ensure children are appropriately served.

In planning to prioritize children for enrollment into Health Homes, the interagency team acknowledged a continuum of severity and complexity of chronic conditions that drive the medical management and the amount and type of self-management and caregiver support required to meet those needs. Medically fragile children are on the high end of the continuum of illness severity and complexity due to their chronic debilitating condition or conditions underscoring the importance of coordination and transitions of their care. Health Homes can meet the unique needs of children and their care coordination needs including chronic conditions faced by the MFC population.

The care coordination services provided through Health Homes are critical to MFC and their families. These include:

- Comprehensive care management
- Care coordination and health promotion
- Comprehensive transitional care
- Patient and family support
- Referral to community and social supports
- Use of health information technology to link services

A set of preliminary programmatic recommendations for Health Homes to meet the needs of children has been developed to primarily address children receiving their care through ambulatory pediatric settings, but are sufficiently flexible to encompass MFC who may receive care in different settings (including children's hospitals, skilled nursing facilities and their homes). The recommendations for Health Homes are currently being reviewed by participating state agencies and will be discussed further with additional stakeholders prior to being finalized.

In August 2012, the MFC Work Group had a discussion with DOH staff about the Health Home care coordination recommendations. The MFC Work Group sought to understand how the proposed Health Home to serve children related to the MFC population, the current models of care coordination available through the waivers, and how Health Home care coordination would align with MFC transition to managed care. The following are the MFC Work Group recommendations pertaining to meeting MFC care coordination needs.

Recommendation #1: Utilize the Health Home model to provide care coordination for MFC, prioritizing assignment to children who are eligible for Health Home services but are currently not receiving care coordination.

This recommendation will ensure MFC and their families have access to critical care coordination benefits. Children who are enrolled in Medicaid waivers receive care coordination services in those waivers, but may choose Health Home services. However, there is a significant number of MFC who are currently not receiving any individualized care coordination services. Over 25 percent of the total Medicaid spending for MFC involves costs for children who are not in waivers, or receiving care by a MFC provider (i.e. pediatric hospital, specialty hospital, intermediate care facility, LTHHCP, CHHAs, private duty nursing etc.). This population would be prioritized for Health Home services. Health Homes should assure that children are assigned to care coordinators with expertise in serving children and their families.

Next Steps

The Department of Health in partnership with the Office of Mental Health and Office of Alcoholism and Substance Abuse Services will develop recommendations for the provision of Health Home services to eligible children and conduct external outreach with stakeholders for feedback. It will be important for Health Homes to demonstrate to the State their expertise and

capacity to serve children, including those children with frequent, special and complex needs. All Health Homes are required to meet all the conditions specified in the Health Home Provider Qualifications and Standards. Before a Health Home is approved to serve MFC, each Health Home network will be screened by means of an application process that requires a detailed explanation about the adequacy of serving the MFC population. The application will focus on care coordination to avoid fragmented care, the addition of new services/providers to the network that have prior experience with children and families, and ensuring that current care is being provided to MFC will not be jeopardized by the move to a Health Home network. Health Homes meeting the State's requirements will be able to engage high need, high cost MFC, and their families can benefit from these critical services.

Recommendation #2: Allow CAH I/II, III, IV and VI children that are enrolled in Managed Care to retain their waiver services until such time as the waivers end and are transitioned to Managed Care. Beginning in 2016 the CAH I/II and the consolidated CAH III, IV, and VI waiver populations are scheduled to transition into Managed Care. At that time, care coordination and other waiver services (e.g., respite, palliative care (specific to CAH I/II), and environmental and vehicle modifications) will still be available to this population as part of the Managed Care benefit package (thanks to benefit integration). DOH will include a contractual obligation for the Managed Care Plan to designate, or work with, the care coordinator or Health Home to monitor and ensure the provision of all needed services to the CAH population. To smooth the transition to Managed Care and ensure continuity of care, Plans would be required to pay the existing care coordination fee-for-service rate for one year.

This recommendation will maintain continuity of care coordination, health and supportive services for those MFC who are transitioning from fee-for-service Medicaid into managed care and those children who are already in Medicaid managed care until the waivers devolve. It will also ensure that care coordination advocates and managers can remain directly involved in the care of MFC and that there is effective communication among care coordinators and the Managed Care Plans or a Health Home as appropriate.

Next Steps

DOH will modify the model contract between DOH and Managed Care Plans to require the plans to have a contractual obligation for care coordination services either with the CAH Case Manager or Health Home as appropriate to communicate and monitor care activities of their enrollees. The contract would specify the Managed Care Organization (MCO) responsibility for care and services and the waiver responsibility for the services not covered in the MCO benefit package (e.g., care coordination, respite, home adaptations, and vehicle modifications).

Transition to Managed Care (Recommendations #3 and #4)

Background
Work Group discussions regarding the transition of MFC to Medicaid Managed Care (MMC) primarily focused on the following four general topics:

- MMC Plans should be fully informed and educated about the complex health care needs of MFC,
- MMC contracts should appropriately reflect the standards of care for treatment of MFC and care should take into account the special needs of the MFC population,
- Administrative procedures related to the timeliness of payments and approvals of claims and the fragile financial status of some of the MFC providers, and
- MMC payment for services should be adequate.

To address the issues imbedded in each of these four general topics the Work Group developed Recommendations #3 and #4.

Recommendation #3: Establish an Advisory/Implementation Committee comprised of Managed Care Plan representatives, providers, consumers and DOH and OPWDD staff, to ensure smooth transition of MFC to Managed Care.

The Advisory/Implementation Committee will provide a forum to:

- Facilitate readiness by providing a direct dialogue between providers and plans to ensure a comprehensive understanding of the complex medical and social needs of the MFC population. Discussions would include the consistent application of Pediatric Care Guidelines which are consistent with Medicaid and Federal standards, including the Early and Periodic Screening, Diagnosis and Treatment standards.

- Discuss the terms of contract provisions for MFC including:
  - How covered services should be indentified to reflect the special nature and needs of MFC. Examples include the complexities of discharge planning (i.e., parental readiness, training, home adaptations), recognition that a child's maximum functional capacity increases as the child matures, habilitation, diverse pharmaceutical needs, private duty nursing/direct hires, Early Intervention and School Supportive Health Services
  - How administrative procedures should be adapted to ensure the flow of critical health care services to MFC are not disrupted. Examples include review standards (i.e., ensure they are relevant to children/MFC as opposed to adults), the transfer of medical and social records of MFC, prior verification of service needs, appeals process and timely payment provisions.

- Ensure there is adequate network capacity to provide the full range of services unique to MFC needs.

Next Steps
Beginning in February 2013, DOH will arrange the first of a series of MFC Advisory Committee meetings with the members of the MFC Work Group and MMC Plans to facilitate the smooth transition of MFC to Managed Care.

Recommendation #4: Establish Managed Care premiums that are all inclusive and provide sufficient resources to meet the complex needs and range of services required to care for MFC.

This recommendation ensures that Managed Care benefits will be comprehensive and include a full range of services (hospital, clinic, nursing homes) to meet the service requirements of the MFC population. As intended in a Managed Care environment, all providers and Plans will negotiate rates of payments with established fee-for-service, benchmark rates serving as a guide (for more information with respect to pediatric nursing home rates please see recommendation #5 below). In addition:

- Plans will be accountable and contracts will include requirements for ensuring there is an adequate care network of pediatric providers and sub-specialists, and allied health professionals and contractual relationships with tertiary institutions to meet the needs of MFC. DOH will closely monitor network capacity.
- To preserve the continuity of care, contracts will include detailed transitional requirements to ensure the full range of services are provided to patients that are transition from fee-for-service to Managed Care, Managed care premiums will included payments for quality.

Consistent with the objective of Care Management for All, provider specific "carve outs" from Managed Care (e.g., for Blythedale Specialty Clinic and CRC Clinic) would be eliminated. To ensure a smooth transition to Managed Care for these clinics that primarily serve children and their patients, Plans would be required to pay no less than the current fee-for-service rates to these providers for one year or until October 2014. During that time, and consistent with the intent of the current statute and statute proposed with the 2013-14 Executive Budget, the Department will work collaboratively with clinics that primarily serve children to implement regulations to develop new Ambulatory Patient Groups (APGs) rates or an alternative rate methodology. It is anticipated that over time the new methodology would appropriately compensate for comparable services and result in a convergence of clinic rates. The new rate methodology will also provide a transparent benchmark available to clinics and Managed Care Plans as rates are negotiated and pediatric patients transition to Managed Care.

To further ensure readiness and a smooth transition to Managed Care, if the Commissioner of Health deems that following the work of the Advisory Committee (as described in recommendation #3 above) the Plans and providers are not adequately prepared for the transition to Managed Care, he may further extend the timeframe past October 2014 for the transition from fee-for-service rates to negotiated rates between providers and Plans.

Although eliminating select carve outs from Managed Care and creating a level playing field for providers that provide similar services is a natural consequence of Care Management for All, some of the Work Group members suggested that the elimination of the carve out for clinics should be delayed pending more detailed discussions and until its clear all affected parties are ready for the transition. To address these concerns, other recommendations of this Report, including the establishment of the Advisory Committee and the collaborative development of an alternative rate methodology for clinics, coupled with the Commissioners role in evaluating readiness and timeframes for implementation, provide safeguards sufficient for proceeding as recommended.

Next Steps
In accordance with legislation submitted with the 2013-14 Executive Budget develop a new APG or alternative rate methodology for clinics that primarily serve children. In addition, in February

2013, begin work with the Advisory Committee established by recommendation #3 to develop the contractual requirements for ensuring continuity of care and the adequacy of the provider network in meeting the needs of MFC.

Pediatric Nursing Home Rates and Transition to Managed Care (Recommendation #5)

Background

Over the past 18 months DOH has worked with the Nursing Home industry to reform and implement changes to the nursing home reimbursement methodology. Effective January 1, 2012, the outdated, complex and irrational cost-based rate setting methodology for the operating component of the rate for non-specialty nursing homes (those homes that care for patients with needs typically associated with a geriatric population) was replaced with a pricing methodology. Unlike its cost-based predecessor, the new pricing methodology:

- provides for an equitable reimbursement system that rewards efficiencies and incentivizes quality outcomes;
- is predictable and transparent;
- can easily be updated and is administratively efficient for providers and DOH;
- provides a smooth transition from the current cost based rates to the price; and
- provides a rational benchmark price for the transition to managed care.

Specialty nursing homes (or specialty units contained within a nursing homes) include nursing homes/units that provide care for pediatric patients who require extensive nursing, medical, psychological and counseling support services solely to children (i.e., MFC patients); AIDS patients; patients with traumatic brain injuries; patients requiring behavioral interventions; and non-pediatric patients with long-term ventilator needs.

Given the complex nature of the patients served by specialty nursing homes, the specialty homes were carved out of the pricing methodology. Pending the development of a separate pricing methodology that would better account for the different cost structures and needs of patients served by specialty nursing homes, legislation provided that effective January 1, 2012, each such specialty home/unit would be paid the specialty operating rate in effect for them on January 1, 2009, trended to the current rate year, and subject to applicable rate appeals.

The pediatric nursing home rates in effect on January 1, 2012 are based upon the complex cost–based methodology that was in place for non-specialty nursing homes prior to the implementation of pricing. As shown in the table below, the current pediatric cost-based rate setting methodology results in:

- Reimbursement rates for operating costs that are not transparent and vary significantly among providers – rates range from approximately $500 per day to over $1,000 per day.
- Operating costs that vary significantly among providers – costs per day range from $353 to $836 per day.
- The use of base year costs (i.e., the cost year (before trending) used to set the rate) that vary widely among providers – base year costs range from 1983 to 2010.
- Positive and negative gaps between costs and reimbursement rates.
- Rates that are not informed by the case mix of pediatric patients (i.e., the acuity and needs of the patient). There is no tool currently available to appropriately and comprehensively measure the patient acuity of a pediatric patient. Applying the Minimum Data Set (53 RUG Data) used to measure the case mix of adult nursing home patients as a relative "proxy" to compare case mix among pediatric nursing homes (albeit a poor measure but the only data source readily available) suggests that case mix varies among nursing homes but is not always consistent with costs.
- Added staff appeals that are based upon clinical assessments to account for the higher care need of patients has further complicated the methodology.

- A rate methodology that is not linked to and does not incentivize quality care.

Current Pediatric Nursing Home Operating Rates and Operating Costs Vary Significantly						
		Rate		Costs		
Pediatric Nursing Home	**# Beds**	**Base Year Used to Calculate Rate**	**Jan 1, 2009 Rate Effective Jan 1, 2012**	**2011 Adjusted Allowable Costs Per Day**	**2011 Case Mix Proxy 7)**	**Rate Vs. Adjusted Costs Per Day**
Elizabeth Seton 1)	136	2005	$908	$827	1.59	$81
St.Mary's 2011 Cost Report	95	1983	748 8)	836	1.28	(61)
St. Mary's 2012 Proposed Budget	95	1983	748	1,337	Na	(589)
St. Margaret's 2)	72	2000	490	572	1.36	(82)
Sunshine 3)	46	2010	1,003	778	1.44	225
Northwoods 4) (Unit)	36	1989	659	353	1.34	306
Avalon Gardens (Unit)	36	2008	519	501	1.27	18
Rutland 5) (Unit)	32	2004	490	620	1.14	(130)
Incarnation	21	1983	787	735	0.58	52
Highpointe 6) (Unit)	21	1985	488	--	1.27	--

1) Allowable Costs adjusted to reflect added staff included in the 1/1/12 rate
2) Allowable Costs have been adjusted to reflect staff included in the 1/1/12 rate, days have been adjusted to reflect 90% occupancy, and bed size adjusted from 56 to 72 beds (10/01/10)
3) Bed Size has been adjusted to reflect the addition of beds in June and November of 2011. Sunshine is currently operating 53 beds.
4) 1/1/12 Rate reflects budgeted rate – rate will be adjusted to reflect 2011 allowable costs
5) 1/1/12 Rate reflects pediatric rate this is blended with SNF rate, days have been adjusted to reflect 90% occupancy
6) 1/1/12 Rate reflects prior owner rate until such time as DOH receives a budget to establish a rate
7) Case Mix proxy for pediatric patients using 2011 MDS data, counts and geriatric SNF weights from 1993-1997 Federal Time Study
8) Does not reflect 2009 added staff appeal now under review

These aspects of the current methodology and the general absence of a tool or mechanism to measure the patient acuity of pediatric patients present significant impediments to ensuring that every pediatric patient – both now and as the State transitions to Care Management for All - is receiving consistent, cost effective, quality care. To address these issues the Work Group has advanced the following recommendation.

Recommendation #5: DOH and the pediatric nursing homes work together to develop a new pricing methodology for the operating component of the rate that will provide a rational benchmark rate for the transition to Managed Care.

To ensure a smooth transition to Managed Care for these providers and their patients, Plans would be required to pay no less than the current fee-for-service rates to pediatric nursing homes for one year or until October 2014. During that time, the Department will work with pediatric nursing homes to develop the details of a new pricing methodology. The new rates will provide a transparent benchmark available to nursing homes and Managed Care Plans as rates are negotiated and pediatric patients transition to Managed Care.

While DOH and pediatric nursing homes will work together to develop the details of a new pricing methodology, specific parameters would include:

- A reimbursement methodology that is transparent, predictable and stable.
- Initially moving all providers to a rate that is based upon 2011 costs (the most recent cost report year for which data is available). Costs would be collaboratively reviewed by DOH and the provider and may be adjusted where appropriate (e.g. added staff appeals, reimbursable costs under the Medicaid program).
- The development and testing of a patient acuity tool and the development of a wage equalization factor to adjust the price.
- Quality payments/adjustments. The 2013-14 Executive Budget recommends that resources attributable to the elimination of trend factor increases be reallocated to quality initiatives.
- A multi-year transition to the price.
- Consistent with the MRT Waiver proposal and discussions with the nursing home industry, DOH is pursuing a path to carve out the capital component of the Medicaid nursing home rate from the Managed Care premiums. This approach will preserve the legacy capital investments of nursing homes, including those relevant to the recent construction and reconfiguration of four (St. Mary's Hospital for Children, Elizabeth Seton, Highpointe and St. Margaret's) of the nine pediatric nursing homes.

Next Steps

Legislation has been submitted with the 2013-14 Executive Budget to implement a new pricing methodology, for pediatric nursing homes. Beginning in February 2013, DOH will arrange the first of a series of meetings with pediatric nursing homes to develop the specific components, including the development of a pediatric patient acuity tool, of a new pricing methodology.

Pediatric Patients Receiving Out-of-State Care (Recommendation #6)

The Work Group discussed the desire to repatriate pediatric MFC patients that now receive out-of-state nursing home care. Over the one year period (July 2011 to July 2012) two nursing homes located in New Jersey and one located in Pennsylvania provided almost $16 million of care to 75 New York pediatric patients. Roughly 90 percent of these patients are high acuity and in need of ventilator care.

Although there are likely several circumstances that lead to the use of out of state nursing homes to care for pediatric patients, including where the family resides (an out of state nursing home may be more conducive for family visits and interaction) it is clear that there is a shortage of pediatric ventilator beds. Of the 501 pediatric beds in New York State –87 are identified as pediatric ventilator beds. These pediatric ventilator beds are generally at full occupancy throughout a given year.

Recommendation #6: Work with nursing homes to establish new pediatric ventilator bed capacity, including long term capacity, aimed at repatriating out-of-state MFC patients.

The MFC Work Group believes this recommendation will:

- Complement the efforts of MRT #68 which is examining the barriers to repatriating all out-of-State Medicaid patients,
- Improve access to critical services to obviate the need for out-of-state placements of MFC and provide the opportunity to bring MFC closer to their families,
- Improve clinical relationships between New York State nursing homes and the MFC's primary care physician, and
- Create job and business opportunities for New York State nursing home operators.

In conjunction with developing new vent bed capacity for pediatric patients, members of the Work Group suggested it would also be important to consider:

- Developing regulations to prescribe staffing levels and competencies,
- Requiring pediatric vent facilities to accept respite admissions to assist in improving the quality of life of families,
- Developing programs for ventilator dependent children that age-out, and
- If home care programs can be developed or modified to enhance the care of pediatric ventilator patients.

Next Steps

Beginning in February 2013, meet with interested nursing homes to develop and implement a work plan to establish new capacity for pediatric ventilator beds

Appendix A

Medically Fragile Children Work Group
Chapter 56 Laws of 2012, Part D §34-b

34-b. Workgroup on Medicaid payment for services for medically fragile children.

1. The commissioner of health and the commissioner of the office for people with developmental disabilities shall convene and co-chair, directly or through a designee or designees, a workgroup on Medicaid payment for services for medically fragile children (referred to in this section as the "workgroup") to make recommendations on the adequacy and viability of Medicaid payment rates to certain pediatric providers who provide critical services for medically fragile children including recommendations on appropriate models for care coordination and the transition of the pediatric nursing home population and benefit into Medicaid managed care, including home care agencies affiliated with pediatric nursing homes and diagnostic and treatment centers which primarily serve medically fragile children.

2. The workgroup shall be comprised of stakeholders of medically fragile children, including providers or representatives of pediatric nursing homes, home care agencies affiliated with such pediatric nursing homes and diagnostic and treatment centers which primarily serve medically fragile children (including pediatric rehabilitation diagnostic and treatment centers), representatives of families of medically fragile children, and other experts on Medicaid payment for services for medically fragile children. Members (other than representatives of families of medically fragile children) shall have demonstrated knowledge and experience in providing care to medically fragile children in pediatric nursing homes and diagnostic and treatment centers, including providers who provide care primarily to the Medicaid population, or expertise in Medicaid payment for such services. Members shall be permitted to participate in workgroup meetings by telephone or videoconference, and reasonable efforts shall be made to enhance opportunities for in-person participation in meetings by members who are representatives of families of medically fragile children.

3. The commissioners shall present the findings and recommendations of the department of health, the office for people with developmental disabilities and the workgroup to the governor, the chair of the senate finance committee, the chair of the assembly ways and means committee, the chair of the senate health committee and the chair of the assembly health committee by October 1, 2012 at which time the workgroup shall terminate its work and be relieved of all responsibilities and duties hereunder. During the timeframe in which the workgroup is deliberating, the commissioner of health shall take steps to assist pediatric rehabilitation clinics.

Appendix B

Medically Fragile Children Work Group Members	
Organization	**Work Group Member**
Elizabeth Seton Pediatric Center and CRC	Ms. Pat Tursi
St. Margaret's Center/Center for Disability Services	Mr. Alan Karfchin
Blythedale Children's Hospital	Mr. Lawrence Levine
St. Mary's Hospital for Children	Dr. Edwin F. Simpser
Terrence Cardinal Cooke	Mr. James G. Karkenny
Angela's House	Mr. Robert Policastro
The Center for Discovery	Mr. Patrick Dollard
American Academy of Pediatrics	Ms. Elie Ward
Sick Kids Need Involved People (SKIP)	Ms. Margaret Mikol
Director of Project Delivery of Chronic Care	Ms. Maggie Hoffman
Coalition of Medically Fragile Children	Mr. Jim Lytle
People, Inc.	Ms. Rhonda Frederick
DOH ~ Office of Quality and Patient Safety	Dr. Lawrence Sturman

Appendix C

Medically Fragile Children Diagnoses (DX) Descriptions and Codes			
DX Code	**DX Description**	**DX Code**	**DX Description**
042	HUMAN IMMUNODEFICIENCY VIRUS HIV DISEA	53642	MECHANICAL COMPLICATION OF GASTROSTOMY
1919	MALIGNANT NEOPLASM OF BRAIN, UNSPECIFIED	53649	OTHER GASTROSTOMY COMPLICATIONS
2532	PANHYPOPITUITARISM	5601	PARALYTIC ILEUS
2701	PHENYLKETONURIA PKU	56989	OTHER SPECIFIED DISORDERS OF INTESTINE
27787	DISORDERS OF MITOCHONDRIAL METABOLISM	5780	HEMATEMESIS
28242	SICKLE-CELL THALASSEMIA WITH CRISIS	5789	HEMORRHAGE OF GASTROINTESTINAL TRACT, UN
28264	SICKLE-CELL/HB-C DISEASE WITH CRISIS	586	RENAL FAILURE, UNSPECIFIED
28269	OTHER SICKLE-CELL DISEASE WITH CRISIS	591	HYDRONEPHROSIS
3154	DEVELOPMENTAL COORDINATION DISORDER	59654	NEUROGENIC BLADDER NOS
3158	OTHER SPECIFIED DELAYS IN DEVELOPMENT	71840	CONTRACTURE OF JOINT, SITE UNSPECIFIED
3300	LEUKODYSTROPHY	72781	CONTRACTURE OF TENDON (SHEATH)
3314	OBSTRUCTIVE HYDROCEPHALUS	73010	CHRONIC OSTEOMYELITIS, SITE UNSPECIFIED
3341	HEREDITARY SPASTIC PARAPLEGIA	73018	CHRONIC OSTEOMYELITIS, OTHER SPECIFIED S
33510	SPINAL MUSCULAR ATROPHY, UNSPECIFIED	73679	OTHER ACQUIRED DEFORMITIES OF ANKLE AND
3430	CONGENITAL DIPLEGIA	73730	SCOLIOSIS AND KYPHOSCOLIOSIS , IDIOPATH
3432	CONGENITAL QUADRIPLEGIA	73739	OTHER KYPHOSCOLIOSIS AND SCOLIOSIS
3433	CONGENITAL MONOPLEGIA	74100	SPINA BIFIDA WITH HYDROCEPHALUS, UNSPECI
3434	INFANTILE HEMIPLEGIA	74103	SPINA BIFIDA WITH HYDROCEPHALUS, LUMBAR
3439	INFANTILE CEREBRAL PALSY, UNSPECIFIED	74190	SPINA BIFIDA WITHOUT MENTION OF HYDROCEP
34400	QUADRIPLEGIA, UNSPECIFIED	7421	MICROCEPHALUS
34409	OTHER QUADRIPLEGIA	7422	CONGENITAL REDUCTION DEFORMITIES OF BRAI
3441	PARAPLEGIA	7423	CONGENITAL HYDROCEPHALUS
3449	PARALYSIS, UNSPECIFIED	7424	OTHER SPECIFIED CONGENITAL ANOMALIES OF
34510	GENERALIZED CONVULSIVE EPILEPSY, WITHOUT	7467	HYPOPLASTIC LEFT HEART SYNDROME
34511	GENERALIZED CONVULSIVE EPILEPSY, WITH IN	7470	PATENT DUCTUS ARTERIOSUS
3481	ANOXIC BRAIN DAMAGE	7483	OTHER ANOMALIES OF LARYNX, TRACHEA, AND
34830	ENCEPHALOPATHY, UNSPECIFIED	7503	TRACHEOESOPHAGEAL FISTULA, ESOPHAGEAL AT
34831	METABOLIC ENCEPHALOPATHY	7513	HIRSCHSPRUNG'S DISEASE AND OTHER CONGENI
34889	OTHER CONDITIONS OF BRAIN	7542	CONGENITAL MUSCULOSKELETAL DEFORMITIES O
3499	UNSPECIFIED DISORDERS OF NERVOUS SYSTEM	75671	PRUNE BELLY SYNDROME
3590	CONGENITAL HEREDITARY MUSCULAR DYSTROPHY	7582	EDWARDS' SYNDROME
3591	HEREDITARY PROGRESSIVE MUSCULAR DYSTROPH	7597	MULTIPLE CONGENITAL ANOMALIES, SO DESCRI
4168	OTHER CHRONIC PULMONARY HEART DISEASES	75989	OTHER SPECIFIED CONGENITAL ANOMALIES
4275	CARDIAC ARREST	76503	EXTREME IMMATURITY, 750-999 GRAMS
4293	CARDIOMEGALY	769	RESPIRATORY DISTRESS SYNDROME IN NEWBORN
4321	SUBDURAL HEMORRHAGE	77081	PRIMARY APNEA OF NEWBORN
45340	ACUTE VENOUS EMBOLISM AND THROMBOSIS OF	7792	CEREBRAL DEPRESSION, COMA, AND OTHER ABN
45341	ACUTE VENOUS EMBOLISM AND THROMBOSIS OF	7797	PERIVENTRICULAR LEUKOMALACIA
4539	OTHER VENOUS EMBOLISM AND THROMBOSIS OF	78031	FEBRILE CONVULSIONS (SIMPLE), UNSPECIFIE
47874	STENOSIS OF LARYNX	79902	HYPOXEMIA
5119	UNSPECIFIED PLEURAL EFFUSION	82101	CLOSED FRACTURE OF SHAFT OF FEMUR
5180	PULMONARY COLLAPSE	85400	INTRACRANIAL INJURY OF OTHER AND UNSPECI
51883	CHRONIC RESPIRATORY FAILURE	85401	INTRACRANIAL INJURY OF OTHER AND UNSPECI
51884	ACUTE AND CHRONIC RESPIRATORY FAILURE	V440	TRACHEOSTOMY STATUS
51900	TRACHEOSTOMY COMPLICATION, UNSPECIFIED	V441	GASTROSTOMY STATUS
51909	OTHER TRACHEOSTOMY COMPLICATIONS	V4611	DEPENDENCE ON RESPIRATOR, STATUS
53640	GASTROSTOMY COMPLICATION, UNSPECIFIED	V550	ATTENTION TO TRACHEOSTOMY
53641	INFECTION OF GASTROSTOMY	V551	ATTENTION TO GASTROSTOMY

Appendix D
Medicaid Expenditures and Utilization for MFC Managed Care recipients by Major Categories of Service
MMC Children and Non Duals

Service Dates: January 2011 - December 2011

Source: NYS DOH/OHIP Datamart (based on claims paid through 8/2012)

SURS Category of Service	Medicaid Expenditures	Total Service Units (Claims or Days)	Medicaid Recipients
All Medicaid Categories of Services	**$131,353,578**	**n.a.**	**7,013**
Physicians	1,415,038	24,671	1,088
Psychology	4,273	81	17
Eye Care	3,982	192	52
Nursing Services	1,248,173	4,766	32
Hospital Based Clinics	4,476,856	18,422	1,881
ER*	292,177	1,228	571
D&TC Clinics	4,199,752	27,754	1,773
OMH Operated Clinic	28,250	76	7
OPWDD Operated Clinic	359	3	3
School Supportive Health Services Program	489,060	18,662	198
Early Intervention	10,106,930	118,528	1,191
Inpatient	54,028,675	48,204	3,596
OMH Inpatient	134,618	99	7
OPWDD Developmental Centers	0	0	0
Skilled Nursing Facilities	3,466,978	4,754	37
Residential Treatment Facilities	128,149	575	3
Dental	656,700	7,608	1,622
Pharmacy	17,503,317	117,730	6,615
Non-Institutional Long Term Care	1,727,913	14,596	290
Personal Care	1,005,285	9,255	51
Home Care	659,954	4,730	245
Long Term Home Health Care	62,674	611	5
ALP	0	0	0
PERS	0	0	0
Laboratories	152,778	3,280	464
Transportation	553,420	7,445	585
HMO	24,298,107	74,918	6,993
CTHP	177,047	3,662	798
DME and Hearing Aid	1,319,055	10,432	787
Child Care	53,979	2,176	16
Family Health Plus	100,264	344	53
Referred Ambulatory	296,949	956	301
ICF-DD	201,679	475	2
Hospice	197,275	67	10
Community/Rehab Services	2,093,096	6,003	112
Case Management	2,169,490	40,645	1,482