

**To Review and Advise on the Implementation of
New Hampshire's Medicaid Care Management Program**

**MINUTES
December 10, 2015
Legislative Office Building
Concord, NH**

Welcome and Introduction

The meeting is called to order by Commissioner Mary Vallier-Kaplan at 1:05 pm. Present in addition to Commissioner Vallier-Kaplan is Donald Shumway, Nicholas Toumpas, Doug McNutt, Thomas Bunnell, Yvonne Goldsberry, Susan Fox, Gus Moral, Roberta Berner, Ken Norton, Wendy Gladstone, MD., and Jo Porter.

Commissioner Vallier-Kaplan introduces herself and welcomes everyone to the meeting. She then asks the Commissioners and public to introduce themselves.

She addresses the audience and states some of you come every month and some are new. This Commission was set up by the Governor for recommendations and oversight for Medicaid Care Management. We have been meeting for three (3) years in April or May. Commissioner Vallier-Kaplan explains the structure of the meetings and the types of issues that the Commission focuses on. She states that the Commission tries to engage the audience in the discussion and saves time at the end for Questions and Answers.

Commissioner Mary Vallier-Kaplan references the minutes from the November 12, 2015 meeting. Commissioner Susan Fox states that she made some minor edits to the minutes. A motion was made to accept the minutes of November 12, 2015. The minutes were seconded and approved by the Commission.

Commissioner Vallier-Kaplan references two letters that were sent to the Commission, one on transportation and the other a follow-up to Ms. Cathy Spinney's concern that she presented at the last meeting regarding long term prior authorization. Commissioner Vallier-Kaplan states that she has received feedback from the Department on both letters. The issue related to transportation was not systemic and the Department dealt with it. The other issue is a systemic issue that the Commission workgroup is reviewing. There will be more detail presented later in the meeting and the Commission will continue to follow this issue.

Commissioner Vallier-Kaplan acknowledges that this is the last meeting that Commissioner Nick Toumpas will be attending. She states that he has been a part of the Commission from the beginning of the implementation of care management. Commissioner Vallier-Kaplan thanks Commissioner Toumpas for his leadership in directing his staff in relation to the Commission. She states that this has been a great example of how a Commissioner can provide guidance and support to a Commission making it an effective method to connect the implementation of an important program with the public, the Governor and the DHHS. She continues that it would not have been collaborative without his leadership.

Commissioner Nick Toumpas responds that anything of this magnitude is a huge team effort. There have been many people that have made this happen. He continues that the Department is wedded to its mission

and he is proud of the work that his staff has done. He explains that the Department listens to every comment that the Commission makes and he thanks the Commission and states that the gift that can be given is to continue forward with this work.

Commissioner Vallier-Kaplan then turns the meeting over to Commissioner Toumpas to give his monthly update.

DHHS MCM Update

Commissioner Toumpas opens by reviewing the agenda. He explains he will review the monthly enrollment numbers, give an MCM update, Pharmacy/NEMT Authorization Update, MCM Opioid Policy/Authorization update, and discuss workforce development.

Monthly Enrollment Update

Commissioner Toumpas states that the Care Management program has been in place for 25 months. As of December 1, 2015, there were 16,387 individuals enrolled in the MCM program. This is the traditional Medicaid population along with the NH Health Protection Program population. There are 19,887 enrolled in Medicaid but not enrolled in MCM. In terms of MCM program enrollment by plan, Well Sense has 87,908 members enrolled and New Hampshire Healthy Families has 73,479 members enrolled.

NHHPP Update

Commissioner Toumpas states that there are 44,135 recipients enrolled in NHHPP as of December 4, 2015. There are 41,109 in the Alternative Benefit Plan with 2,594 medically frail. Commissioner Toumpas then reviews the Step 2, Phase 1, Mandatory Enrollment numbers. He states that there are currently 3,034 enrolled with 1,325 with Well Sense and 1,709 with NHHF.

MCM Contract Amendment Update

Commissioner Toumpas states that a contract amendment is required for MCO coverage of the Medically frail to be effective for 1/1/16. There is another amendment targeted for 2/1/16 to enable a sub capitation arrangement between the MCOs and CMHCs and a future amendment required to implement copays.

Why Care Management?

Commissioner Toumpas discusses the slide entitled, Why Care Management? The goal of care management is to improve access to care, as well as quality of care and overall health status. It is also to improve cost effectiveness. Commissioner Toumpas opens the session to questions from the Commission and audience. There were no questions.

Effective Operations Subgroup: Pharmacy/NEMT Authorization Update

Over the past several months there have been questions raised by the Commission regarding prior authorizations related to pharmacy and with the Department's Quality Division there has been an alignment with work that is being done by the Department and the MCM Commission. Commissioner Yvonne Goldsberry leads the Effective Operations Group along with Commissioner Tom Bunnell, and Commissioner Gus Moral. Commissioner Goldsberry states they are focusing on three (3) areas with the top issue being Prior Authorizations. She continues that in the past the subgroup never asked the Department for a full briefing on this subject but recently she along with Commissioner Bunnell, Dr. Doris Lotz and Ms. Deborah Scheetz met to do a deep dive on the subject. She states that group asked the

Department to provide data that was never received before on pharmacy and Non-Emergent Transportation (NEMT). The subgroup is working with Ms. Deborah Scheetz and has researched what other states are doing. The group has also discussed the difference between habilitation and rehabilitation. Today Commissioner Toumpas will present more information on pharmacy and NEMT. Commissioner Goldsberry states that there will be time for questions after Commissioner Toumpas presents. Commissioner Toumpas points out that currently the Department has been focusing on outcomes. He states that several individuals have been brought into the Department to work as focal points including Ms. Deborah Scheetz. He then states that all the materials he will be presenting will be on the Governor's and Department's website. He goes on to explain the graph entitled MCM Pharmacy Claims, Authorizations and Appeals and stresses 2015-Q2 results stating that there were 974,270 total pharmacy claims with 10,496 subject to Service Authorizations. Of those 4,025 were denied authorizations with 293 appeals and 120 appeals upheld. Commissioner Toumpas then references the top 10 drug classes for MCM pharmacy service authorization denials. He states that the overwhelming majority of pharmacy claims do not require service authorizations and very few claims are denied or appealed. Antidepressants largely prescribed by Primary Care Providers (PCP's) is the one behavioral health medication in the top 10 denied drug categories. Commissioner Toumpas then discusses ad hoc reporting that was previously presented to the MCM Commission in July 2015. This reporting indicates that 46-59% of denials are being given for business reasons. An example of this is a preferred drug is available and there is no coverage for the drug requested. The reporting also indicates that 41-53% of denials are for clinical indications such as medical necessity not being met. Commissioner Toumpas comments that as of October 1, 2015 each MCO runs their own drug pharmacy list and is not required to strictly adhere to the NH Medicaid Preferred Drug list. Commissioner Toumpas reviews the NEMT Requests, Authorizations, Appeals, and Grievances slide. Many of the previous issues related to transportation have been resolved since both MCOs now use the same transportation vendor. Total request in 2015-Q2 were 131,027 with all requiring authorizations. Of those 125,010 were delivered and 478 were denied. Commissioner Toumpas reviews the Non-Emergent Medical Transportation slide. NEMT utilization has increased since the onset of the MCM program, primarily due to NHHPP population. All NEMT requests undergo authorization review and very few NEMT are denied. There are very few NEMT appeals, fair hearings and grievances with many a result of one transportation vendor. A new transportation vendor began in 2015- Q3 with one of the MCOs.

Commissioner Roberta Berner asks how many of the 131,000 rides were given by family or friends.

Commissioner Toumpas responds that he will get that information for her.

Commissioner Ken Norton asks if these numbers include behavioral health.

Commissioner Toumpas responds that they do not.

Commissioner Norton asks Commissioner Toumpas if he can explain why anti-convulsants were and what would be the alternative?

Commissioner Shumway responds that well established drugs may have gone to generic and the MCOs want to see choices and which drug is most effective.

Commissioner Norton responds that wouldn't that show the same challenges with anti-depressants that were prescribed something by the doctor and it was then changed?

Commissioner Yvonne Goldsberry states that her subgroup will be watching these numbers closely. She also states that what impressed her most was how few denials there were.

The question was asked how these appeal numbers compare to national numbers. Commissioner Goldsberry responds that now that there is data the subgroup can begin to do a deep dive and benchmark other states.

Commissioner Norton references the pharmacy statistics and states that Commissioner Toumpas mentioned mental illness but was curious as to why ADHD was not considered.

Ms. Kathy Sgambati raises concerns about someone who has lifelong prescriptions and getting prior authorizations for these.

Commissioner Goldsberry remarks that the subgroup has had robust discussions about chronic/acute medical service authorizations and that the group is asking those questions about pharmacy, OT and PT and they are looking at routine prior authorizations versus long term authorizations.

Commissioner Toumpas moves on to the topic of MCM Opioid use as it relates to contract standards and quality measurements. Commissioner Toumpas states that the Department is using the all payers claim data base which allows a look at all the opioid use. The Department is looking at what types of prescriptions are being written, geographically etc. The MCO contract standards require that as of October 1, 2015 the MCOs shall require prior authorization for high dose opioids prescriptions. Beneficiaries with a diagnosis of Substance Use Disorder and all infants with diagnosis of neonatal addition syndrome (NAS) will be referred by the MCO to care coordination to support the coordination of their physical and behavioral health needs and for referral to SUD treatment. Beneficiaries in an MCO lock-in program will be evaluated for the need for SUD treatment.

Commissioner Toumpas explains the new SUD Quality Measures. These measures will look at the rate of referral to case management for all patients receiving buprenorphine or methadone SUD treatment. The SUD measures will also include the rate of referral to case management for all infants with a diagnosis of neonatal abstinence syndrome and the percent of prior authorized fills and refills for high does opioid prescriptions.

Commissioner Toumpas reminds the Commission and the public of the DHHS mission which is “To join communities and families in providing opportunities for citizens to achieve health and independence.” Commissioner Toumpas explains that it is all about the people and it is essential to have workforce adequacy to be able meet the mission of the Department. There is currently a pediatric nursing shortage but it is not only pediatric nursing where there is a challenge. Workers are getting older and there are not enough new workers to replace them and this is becoming more of a challenge. Commissioner Toumpas highlights a strategic initiative for workforce development. He states that the mission is to put the right skilled nurses, and health workers, in the right places, including New Hampshire Hospital, the community, and homes, for the best possible outcomes for those in need and their families. The first step to prepare for future needs is to begin to recruit a multi-skilled, diverse workforce now to keep pace with the state’s integrated health care delivery that reflects emerging population trends and needs. Then establish a DHHS Workforce Development Program to support New Hampshire’s integrated health care delivery system by educating, preparing, and advancing multi-skilled workers ensuring high quality health care. Commissioner Toumpas explains that every day the Department gets a tally of the number of people in Emergency Department’s that are waiting to get into NHH. They do not belong in the ED. The State recognized this and provided dollars for an inpatient crisis psychiatric unit with ten (10) beds which are empty because we cannot hire nurses to staff this unit. Today we are going to speak about the pediatric nursing shortage, but this is a larger issue.

Commissioner Toumpas opens the meeting up to questions.

Commissioner Don Shumway states that he appreciates the update on availability of drug treatment. Under NHHPP the SUD benefit is offered. The Legislature authorized expansion of this benefit to take effect for the Standard Medicaid population on July 1, 2016. This is a great opportunity and stakeholders are engaged. When the Department stands up this benefit there will be 139,000 people eligible to receive it.

Commissioner Tom Bunnell asks when the third MCO will be brought on.

Commissioner Toumpas responds that this is still pending and that under the Request For Application (RFA) any additional entity would have to assume the rates and everything else in the current contracts. This has been put on hold as there have been competing priorities at this time.

Comment from the public: The individual states that they are struggling like every other home health agency and if they could work with the Department together it would be phenomenal. The individual states it is important to get really creative to solve these issues.

Commissioner Norton asks if he can have more detail regarding the CMHC's and the contracts.

Commissioner Toumpas states that the Department is having regular meetings with associations and Deputy Commissioner Marilee Nihan will provide more information as she has been working with the MCOs.

Deputy Commissioner Nihan states that the Department has been meeting regularly since September and now the actuaries have been brought into the mix and found interesting trends in the CMHC data that was not evident before. The three challenges include: 1) incorporating the mental health dollars into the capitation rate, 2) not having a savings to associate with CMHC's and 3) duals are an expensive population and CMHC's have a high rate of duals. This matters to them as we move forward with Step 2. We have made a lot of progress and developed a relationship and are in agreement with a solution. We are currently in the process of doing a contract amendment in phases. Next week we will update some rates in the contract for the medically frail and bring forward the mental health fix in January which will be effective on February 1, 2016.

Commissioner Ken Norton asks if the Department is monitoring the fiscal impact of this.

Deputy Commissioner Nihan states yes. We are monitoring the fiscal conditions of the CMHC's . They had communicated that the capitation model had been helpful because it is a prospective model and since July we have been in a Fee for Service model which is retrospective and has been stressful for the centers.

Commissioner Toumpas states that this is monitored on a monthly basis.

Commissioner Norton asks if the contract amendment is live on February 1st and Deputy Commissioner Nihan reply's that this is the plan.

Step 2 Update

Ms. Lorene Reagan summarizes the history of the managed care program which started in 2013 with the voluntary group moving from FFS to managed care. There were about 10,000 that opted out of managed care at that time as it was not mandatory for them to enroll. Now these individuals are required to enroll with one of the Managed Care Organizations (MCOs). She states that her presentation will summarize what has been done to date for MCO readiness. Currently both health plans have been serving individuals. Ms. Regan explains the bar graph showing the population that is already enrolled with the MCOs. She

states that she wanted to recognize this as she moved through the presentation. Ms. Reagan reviews the nursing facility group and states that about 1,100 individuals did not opt out of managed care but 2,500 did opt out. The Foster Children have mostly already opted in and the Katie Becket children still have about 650 in the program that are in FFS. The emphasis is that the MCOs are already serving this population with complex needs. Ms. Reagan discusses plan coverage readiness calls. To date, 100 enrollment calls have been made for individuals with complex needs who are currently receiving services through MCOs. Ms. Reagan explains that we cannot however; assess the plans ability for people that have not yet enrolled. There will be twenty (20) additional calls made for children in Foster Care and Special Medical Services totaling 120 calls (60 calls to each MCO) by December 18, 2015. Plan coverage call questions cover areas such as HIPAA compliance and Guardianship/legal representative for the member, identification of complex needs of the member, care coordination, out of network requests, questions related to co-pay issues, NEMT policy, and 72 hour emergency supply of medications, prior authorization for medications and the grievance process. In addition to the areas listed above, both plans were further challenged in areas related to vendor performance such as pharmacy, transportation and durable medical equipment.

Ms. Reagan explains in addition to the above there are secret shopper calls. To date a total of 38 calls comprised of 286 total elements have been completed to assess the general shopping experience for a health plan. The Secret shopper call questions cover care and disease management for members with substance abuse and behavior health challenges, reviewing special benefits such as fee cell phones, fitness and weight management reimbursement, new mom's programs, transportation benefits details, assisting with potential pharmacy issues, assessing both in-network and out-of-network specialists and information about filing grievances and appeals.

Ms. Reagan discusses the case file reviews which are also a part of MCO readiness. The Department conducted 30 comprehensive case reviews from 12/7/15-12/9/15 with a team of reviewers. The team reviewed 15 cases at each plan, five (5) were selected by the MCO and ten (10) were selected by the Department. The purpose of the case reviews is to identify systems in place at each of the health plans which inform the Plans of the special needs of their membership. The next readiness project will focus on the Department surveying the newly enrolled members with questions related to MCO performance to provide feedback to MCOs on strengths and weaknesses. Ms. Reagan explains the High Touch process. The Department sends a monthly enrollment report to Behavioral Health Agencies, Area Agencies, CFI Case Management Agencies, DHHS Agencies (SMS, DCYF and Medicaid Medical) and Nursing Facilities. Agency staff identifies "high touch" people who are newly enrolled in a plan and then schedule meetings with the MCOs to discuss individualized needs. To date 118 people have been discussed with MCOs at High Touch Transition meetings between the services agencies and the MCOs. Agency staff reaches out to those individuals who are not enrolled to encourage them to select a plan. Self-selection is at approximately 39%. Other readiness points include guardianship and Authorized Representative information transfer, external communications and messaging and capacity of the Department's Client Services. The transportation workgroup was highly successful with nursing facilities. There were two additional forums held in November and December. There were also member focused information's sessions held in November at People First of NH and upcoming client and provider sessions for December. There has also been extensive training and education with MCOs and the Department collaboration on participant protections. Guardianship training was conducted in October and there will be level of complexity training and New Heights training for MCOs in the near future.

Ms. Reagan states that the MCOs will present today on what they are doing for readiness and introduces Ms. Carol Iacopino representing WellSense Health Plan. Ms. Iacopino begins by explaining the welcome process that WellSense uses for new members. She states that they created a new welcome process to include members with future eligibility dates. Welcome packets are currently going out to members with ID cards. The NH member service team is located in Manchester, NH. WellSense has weekly team

meetings to discuss the calls and to identify any barriers or opportunities for enhanced education to all team members for continuity. There is on-site readiness with DHHS team including case reviews and weekly operation meetings with all WellSense departments and vendors including pharmacy, transportation, DME to ensure consistence in messaging and identify potential barriers to smooth transitions. Ms. Iacopino explains that there are collaboration meetings on high touch with DHHS staff and agency staff to prepare for members with many transitional needs. WellSense is looking at claims data as individuals enroll and looking at utilization data. Social care managers including CFI, DD, and Special Needs all participate in the transition meetings. Beacon Health, WellSense's behavioral health vendor, participates in similar high touch meetings with Community Mental Health Centers and coordinates care for incoming members.

Ms. Reagan introduces Ms. Candance Reddy from New Hampshire Healthy Families (NHHF). Ms. Reddy states that NHHF is ready for Step 2 thanks to the Department's rigorous readiness process. She states that NHHF and the Department have spent a lot of time together over the last year planning for this transition of voluntary population to mandatory. She states that NHHF and the Department went through individual cases to see where their case managers were being helpful and she explains that they have worked hard to make sure their processes are clear. Ms. Reddy continues that NHHF's focus over this time period is to help members live independently.

The meeting is open for questions from the Commission and public.

There are no questions.

Commissioner Shumway states that one thing that the Commission has discussed is to have the MCM Commission meeting at the MCO locations. This should happen in early 2016.

Commissioner Mary Vallier-Kaplan announces the meeting will break for 15 minutes.

Pediatric Home Nursing

Commissioner Vallier-Kaplan reconvenes the meeting. She states that the Commission has developed various subgroups to work on various issues. One of the workgroups has focused on network adequacy. Commissioner Wendy Gladstone has been leading this workgroup along with Commissioner Jo Porter and the Commission asked the workgroup to take a look at the issue of pediatric home nursing. Commissioner Gladstone is introduced by Commissioner Vallier-Kaplan. Commissioner Gladstone states that during the fall the Commission learned that the Department of Health and Human Services has been receiving letters and calls from families that have children with severely complex medical conditions. She continues that these families are having difficulty finding and retaining nurses to provide in home services for their children. The families asked the Department if they would take action on this issue and if the issue could be brought in front of the MCM Commission. The network adequacy subgroup became involved and the Commission will be hearing today from a number of families in very personal terms as to what it means to have trouble getting a nurse in their home to help with a medically complicated child for hours that have already been approved. The Commission will also hear from providers of in home services and members of the MCOs will tell us what they have been doing related to this issue. The Commission will also hear from the Departments Ms. Deb Scheetz and Deputy Commissioner Marilee Nihan. This will be a condensed version of what is going on. The families are also concerned about the Step 2 transition. Many families are here to speak today about their situations. Commissioner Gladstone states that there are providers here to also speak of their challenges.

Families are invited to come forward and introduce themselves to give testimony.

Ms. Heather Donnell introduces herself as the mother of Lucas from Rochester NH. She brought a picture of Lucas. He is active and filled with life. She states that she has a full testimony to read but they had a traumatic day yesterday that must be expressed first. Lucas has Downs Syndrome and ADHD. He is on medication and it is the only thing that keeps him balanced. He had his airway reconstructed in March. He was in a medically induced coma for three weeks. He has a trach, breathing tube and g-tube. This is the only way he gets his nutrition. In March it was a hard decision to give him a trach. But it was a second chance at life. Ms. Donnell states that the one thing that got them through was they were told they would have nursing care and they were told they would have 24 hours if they needed it. They talked to the agency and the Department and all agreed that 80 hours a week would be sufficient, enough to allow her to sleep at night so she could manage Lucas during the day. She explains that they have not had any nursing for 21 weeks. This is over 1600 hours of time she has cared for him on her own along with the other 24 hours of care. She goes on to explain that the prior day, Lucas took his trach out without her knowing. She could not get the trach back in. She called 911 and he was air lifted to Boston. He had to go to Mass General on his own without his parents. The EMT forced the trach into his airway. The blood was everywhere. They held him down and they shoved the trach in. She states that she beats herself up because she had not checked on him 10 minutes before. If they had a nurse this would not have happened. This is a huge issue, emotionally, physically and financially. She states that she has been out of work and she is asking that a short term goal be put into place to pay for their time. Trying to provide for the family is difficult without being able to work. Not having adequate nursing care is impacting both the parents and the children in families.

Commissioner Don Shumway asks if the written testimony could be left with the Commission so it can be distributed to the Commissioners.

Ms. Audrey Gerkin introduces herself and states that she lives in Brentwood with her husband and three (3) children. Her oldest, Lexi is 14 years old and was born with Cornelia de Lange Syndrome and PCDH 19 Female Epilepsy. Two years ago she was placed on palliative care due to regression in her health and a severe swallowing disorder. Lexi is unable to put food and water in her mouth or stomach. She is fed through a G-J tube. She must have multiple inhalers each day to keep her lungs clear. She has received home health care assistance for the last 12 years, by LNA's, LPN's and RN's. Medicaid has determined that her medical needs qualify her for 60 hours of nursing care per week. She is receiving none of these hours. In the last year the Gerkin family has been through 13 nurses and most of them came to their home untrained and inexperienced. Ms. Gerkin and her husband spent a lot of time training them, only to have them leave either because they moved or for higher paying jobs and health insurance. Some of them never could get a handle on the basics of taking care of Lexi. Ms. Gerkin explains that last year Lexi was sent by ambulance to Portsmouth Hospital because she was choking on a toy. She explains that this would not have happened if there was a nurse in their home. Lexi does go to school but the school cannot find nurses to escort her so Ms. Gerkin spends four (4) hours on those days where Lexi goes to school driving her. Due to the stress of the constantly revolving door of poorly trained nurses and lack thereof, as well as the complex medical demands of Lexi's healthcare without appropriate services in place, the Gerkins made a decision to have Lexi stay at Cedarcrest, a pediatric facility for short periods of time. It is written in Lexi's IEP that if nursing falls through one more time then she will be placed long term at Cedarcrest because it is too difficult for their family to manage Lexi's healthcare. This option would be far more expensive to the state than to raise reimbursement rates to insure quality and stable nursing care at home.

Ms. Catherine Meinen introduces herself as the mother of Zoe, who suffers from the effects of brain cancer and has been eligible for hospice since age three (3). There are only 30 people in United States diagnosed with this type of cancer each year and treatments and medications for her often need prior authorizations as many do not understand why she would need these treatment and/or medications. She has seizures daily and her respiratory system has a history of suddenly not functioning; she is also at constant risk for bone fractures. The brain tumor caused her body to begin puberty at age three (3) and she

grew nine (9) inches and gained forty pounds by the time she was five (5). Her brain chemistry is so decimated that the Meinen family has to regulate it externally to avoid seizures, coma, and death. Zoe's public education has been compromised with difficulty securing qualified nurses to accompany her to school even though it is an abbreviated day. When Zoe has been hospitalized, she has lost her home care nurse to another child who is medically fragile and is home from the hospital. Nurses also need to take sick days and go on vacations, which impact's Zoe's home care. There are other policies in place that make it difficult for nurses to meet Zoe's needs. OSHA guidelines state that lifting over 50 pounds must be done with two people and/or an assistive device. Zoe weighs 70 pounds and has compromised muscle tone and bone structure therefore, the Area Agency has repeatedly denied requests for home modifications, therefore they do not have an accessible bathroom for her home care workers to safely bath Zoe and nurses are unable to lift her. All this means that, Ms. Meinen, as Zoe's mother is her medical home care provider all day every day without being reimbursed for her expertise and time. The financial, physical, and psychological ramifications of this are immense and lifelong. Currently, the State excludes parents from the pool of eligible providers and the State's largest home care provider agency cannot provide services for Zoe because their policy is to protect their nurses. They will not send a nurse to their home because Zoe weighs 70 pounds. Ms. Meinen states that she respects this but Zoe has lost this entire pool of home care providers. So the already serious shortage is even worse for Zoe in that respect. Ms. Meinen does not know if the State assumes that if a parent were to be paid as a personal care attendant or specialist that they are trying to take advantage of the system. It has been suggested to some parents that they put their children in long term care facilities. She asks how anyone would feel putting their child in a facility that is two (2) hours away from home. It would be extremely offensive. Ms. Meinen states that if she were recognized as her daughters personal home care attendant and paid in conjunction with other home care workers the state would make enormous progress in fulfilling its commitment to allow Zoe to live at home if this is their choice. Ms. Meinen thanks the Commission for their time.

Ms. Melissa Hinebauch introduces herself and thanks the Commission. She states that she lives in Concord with her husband and three children. She does not have a medically fragile child, but she is a mother and taxpayer concerned about this issue. Most importantly she states that these Moms are her friends and she care about their children and them. When she first heard about children like Lucas and Lexi and Zoe who have complex, severe medical issues and disabilities, and the fact that they are left to struggle without their daily nursing care, she was outraged and alarmed. How is this possible and legal? How can a fragile child with major medical needs not receive the nursing care he is approved for? Ms. Hinebauch continues that it is difficult for these families as they are forced to learn things like having to put a trach tube into a child's neck and are responsible for their child's health because there are no nurses available. Like yesterday, Heather was forced to take care of Lucas's very survival because there are no nurses available. Children like Lucas have been approved for upwards of 80 hours of in home nursing care a week and they are receiving nothing. These parents have to quit their jobs, give up their careers and incomes, to cover for the nurses who never show up. Ms. Hinebauch states that as a taxpayer she is concerned that without nursing care, some of these families will be forced to send their children to long term care facilities. The daily cost of taking care of a medically fragile child at a facility is much more than keeping these children at home with their families. Ms. Hinebauch then refers to the numbers and remarks about hearing in the news about economic development, building jobs in NH, and decreasing the unemployment rate. There is an extraordinary high demand for nurses. There are more nursing jobs to fill, than people to fill them. Why can't NH be known for turning out nurses? This is an economic opportunity for the State. Ms. Hinebauch continues that after what happened to Lucas and Heather, the ambulance, the medical airlift, the hospital stay and the terror to the family, it is fiscally irresponsible and dangerous not to give these families the nursing care they are approved for. Aside from that it comes down to taking care of the children. This comes down to doing the right thing. If NH does not take care of its most vulnerable citizens, what sort of society are we? Ms. Hinebauch asks the Department, the Legislature, the Governor's Office and the MCOs to please provide these children with the nursing care they so desperately need –

today. What happened to Lucas was terrible but don't wait till something worse happens. Please commit to helping these children today.

Ms. Abby Rogers introduces herself and states that she is here as a parent and an advocate for the March of Dimes. She states that her son, Benjamin at the age of four (4) months was diagnosed with Canavan Disease, a progressive neurodegenerative disease. Benjamin died almost 15 months ago at the age of 12. They had nurses working in their home for over 10 years. Ms. Rogers explains that she knows what it is like to find and keep adequate skilled nursing in the home. As Benjamin's illness progressed, his care became more complex and his respiratory assessment needs were 24 hours a day. Although certified for nursing hours, they were never able to fill them. She goes on to state that she was grateful to have a nurse for three (3) days. The rest of the time she was interviewing nurses, tried to recruit nurses, shared nurses with other parents. When they found a good skilled nurse they grabbed them and tired everything imaginable to keep them on their child's case. She stated that they were a lucky family because they had the same caregiver for eight (8) years. Ben's nurse, Ms. Bonnie Calhoun provided advocacy for Ben and education for the Rogers family. Due to the nature of his illness, Ms. Calhoun worked with the Rodgers family to develop a philosophy of care for Ben. Ms. Rogers states that her family was very lucky to have Ms. Calhoun but families should not have to rely on luck. They need stable, skilled nurses to care for their children. Families of medically fragile children often gauge how their child is doing by the number of hospital stays their child has in any given year. Ben, had next to none in the last three (3) years of his life due to their ability to handle his care at home with skilled nursing. Ben's pediatrician told Ms. Rogers that Ben was perhaps the most medically fragile child she has ever had as a patient. His care was PICU level care delivered at home thanks to skilled nursing. Ms. Rogers states that she urges the committee to revise the reimbursement rates for skilled nurses and also pay shift differential. Pediatric home health care is specialty care and those who undertake this important and valuable work should be compensated accordingly. Ms. Rogers then goes on to state that she is the Director of Program Services in NH for the March of Dimes Foundation. This issue is important to them because families that have baby's pre-term leave the hospital with oxygen, trachs, and G tubes and need nursing upon leaving the hospital. Families need education. The trifecta of what the March of Dimes advocates for includes prevention of birth defects, infant mortality and premature birth. One of the issues they have found is maternal stress is a great contributor to premature birth. Most of the women that have children here have younger children and may be going to have more children. Ms. Rogers states that she has a pamphlet that she will give out on material stress.

Mr. Wayne Barrington, Derry, NH asks to speak. He states that he is the grandfather of a 30 month old who is on the Katie Becket program. She has a G-tube and trach. He states that his daughter and son in law work full time. He states that he wants to thank the reliable nurses that are doing a great job and there are some that are not reliable. Coming from a family of nurses he knows that the hospital model has changed. He helps his son with his granddaughter. He is at the point in his life where he can assist them. He does not like to make complaints without having suggestions. He thinks one solution is the idea of paying a parent to care for their children at home. He states that something has to change and hopefully things can happen in a positive manner because people are being challenged with this. Talking with nurses it seems that the shift differential impacts the workforce. He states that he is just coming up to speed with this and he will learn more. He would like to see those nurses that are doing a good job compensated for it. He then thanks the Commission for giving him a chance to speak.

Ms. Karen Hatch introduces herself and states that she would like to give testimony on a long standing challenge in New Hampshire relative to the interpretation of federal regulations relative to the delivery of home services and rules of home health services. Currently, the State of New Hampshire is interpreting the regulation to mean that LNA services cannot be provided outside the home. The interpretation of the federal regulation unnecessarily segregates and isolates individuals that experience disabilities and who are medically challenged and imprisons them in their own homes while denying them access to the

community. The unintended consequences of this are that it denies individuals to a life outside in the community. Families who have LNA services for their child would like the Governor and Council to confirm that CMS and the National Council on Disability to ensure that they provide guidance and further clarification to the state regarding the interpretation of the federal regulation. It is her understanding that the intent of this regulation was not to keep individuals housebound in their homes without any access to the community. Ms. Hatch's daughter Makayla is a teenager whom experiences epilepsy and multiple disabilities. She loves the community and has made relationships in the community but requires an LNA due to her medical needs. Makayla has many friends who have LNAs as well. The results of this interpretation impacts the ability of people who are disabled and medically frail to be able to participate and work on life skills in the community, attend medical appointments, attend family outings, attend playdates with friends or even go outside if they live in an apartment. In the past, LNAs have accompanied individuals in the community while ensuring medical safety. Approximately, three (3) years ago a memo dated July 31, 2012 was issued regarding billing that does not allow for LNAs to accompany recipients to medical appointments. It clearly states that recipients do not need to be home bound but the interpretation was that it did not allow for LNAs to accompany recipients outside the home. Thus, LNA companies were told that they would not be compensated for the time they spent in the community with individuals. Many of the home health agencies do not agree with the interpretation but are forced to follow it so they get reimbursed for the services not subject to punitive action by the state. The explanations and interpretation of the federal regulations and NH rules are confusing and frustrating to the consumer and negatively impacts the lives of individuals being served. The effective individual being homebound and isolated for a period of years from the community is unfathomable. On behalf of the families in the state of NH the Commission is asked to examine the rules and ask CMS to provide clarification and guidance to the state to allow people to access their communities and allow them equal access to the community which is the mission of DHHS.

Ms. Amy Giouard introduces herself and thanks the Commission for hearing the families' testimonies. She states that her daughter's name is Allyson Giouard and she has rare neurologic condition and she is unable to speak and needs assistance. She attends school here in Concord. However, when the school day is over the door is closed and locked to her having access to the community without either herself or Alyson's father being there. She cannot attend an afterschool program because she needs an LNA for personal care and keep her safe. Unfortunately the way the rules are interpreted she cannot go to anything such as brownies, or playdates. It is a disgrace that these children cannot go out in public because of interpretation of the federal regulations. Ms. Giouard asks the Commission to revisit the home health aide regulation and how the State of NH interprets this.

Ms. Kim Habib thanks the Commission for taking the time to listen to the family's issue. She states that their story began 12 years and 10 months ago. They began their journey with many downs but so many ups. Her daughter, Sarah Emily was born four (4) months early. She explains that it was a fragile beginning. They thought that she would catch up and pass all the milestones people take for granted. Sarah started to receive LNA services by the time she was six (6) and this is when she was diagnosed with epilepsy. There were times when the Nursing Agency did not have any LNA's available to do the allocated hours that Sarah needed and Ms. Habib states that she had to manage two agencies to get the coverage she needed to keep her daughter safe and healthy. Sarah had about 47 different LNAs over the years. Ms. Habib states that each time she would have to train them on how to best take care of her daughter. She explains that she has had many LNAs that just didn't care, some had transportation problems, and some really touched their lives in many ways. She continues that they would do everything possible to keep those extra special ones. Many of the LNAs cannot make enough salary to keep it as their only job and therefore have to supplement their income. She states that we need to find ways to compensate these dedicated employees to keep them active in their children's lives. Ms. Habib continues that just this year they received a call from their Area Agency that the "In Home Support Waiver" has an opening. They waited for this for nine (9) years. After discussing the details of how the money could be

spent and how much went to support the current needs of Sarah's personal care, it only left seven (7) hours a month for LNA services. Currently, Sarah is approved for 40 hours a week for LNA services, and is getting 30 hours a week covered. Ms. Habib stated that she had to decline the decision to accept this offer at this time and give it to another family as Sarah could not receive LNA services if she was on the "In Home Support Waiver". This would have been best scenario for Sarah because these caregivers are allowed into the community but the LNA hours were critical.

Mr. Bill DiGiau. introduces himself as the founder of Annie's Angels Memorial Fund and which is based in Stratham. They help local families that are struggling financially with life threatening disease, illness or disability. They connect neighbor to neighbor, friend to friend and business to business in a caring fundraising network. For some people it is just Thursday of committee meetings but for or Annie's Angels families it is another Thursday for a fight between life and death. He addressed the Commission and stated that they should not think about these children as medically challenged or medically complex but as Lucas and Heather, Katherine and Zoe, Lexi and Audrey. Thank you.

Ms. Emily James thanks the Commission for their work. These stories are not easy to hear. She thanks them for taking the time to understand the impact on the home nursing shortage. She explains that her daughter Maya is a vibrant, wonderfully funny and loving young child. However, when she was born in 2005 she was a very sick infant. She was born with Down syndrome and experienced a lot of the medical complications from that. She continues that they spent the first 6 months of her life I the neonatal intensive care units at Dartmouth and Boston Children's Hospitals. At the end of the stay, Ms. James explains that she thought that they had endured what was likely the hardest time of their lives. Then then continues that little did she know that it would get harder. When they arrived home, they were promised 40 hours of nursing support a week. Given that level of support, she was fairly confident that they could care for Maya at home. Because of the home nursing shortage in their rural area, in the first two weeks, they received a total of ten (10) hours. At the end of the two weeks she was exhausted and concerned that Maya would die because of her lack of knowledge or just sheer exhaustion. Ms. James stated that she called everyone which was not easy for her to do. The nursing company said that they didn't have anyone with a LPN nursing credential. Ms. James told them she could train almost anyone and that she just needed a live adult body. They couldn't give her that because Maya required a higher level of care. So Ms. James asked them why it was OK to leave Maya with her as she had only one (1) day of training. Ms. James continues that she was so desperate that she made what she hopes will be the worst phone call she will ever have to make. She broke down with the discharge coordinator at Dartmouth. She told her that just couldn't do it. The discharge coordinator realized the level of her distress and did offer the hours of some of the Dartmouth nurses and she received a nurse for four (4) hours. This brought her up to nine (9) hours a week which still was not enough. Maya had a medical emergency and was airlifted to Dartmouth hospital. This was related to a medication and not anything that Ms. James was responsible for. One of the nurses overheard her talking about the lack of nursing support and whispered to her to refuse to take Maya home and to be honest about her concerns and their inability to safely care for her at home. At that point 20 hours of nursing care was offered to them which was enough to help the family. Ms. James asks the Commission why there is such a nursing shortage. Could it be that it is too hard to get home nursing hours paid for by insurance? Could it be the fact that nurses get paid more and get more regular work in a hospital setting? Could it be that nurses, particularly those on their own in a home setting that are shouldering all the day-to day responsibilities just do not get paid enough? While the overall nursing shortage is bad, to find a pediatric home nurse is even harder. In fact, Ms. James states that she had to personally seek out and find all the nursing help that she needed. She has found these nurses herself by placing ads in nursing schools, talking with people in her community, and talking with school nurses. She explains that one of the top three most challenging aspects of being her daughter's mother is finding nursing support. Please consider that this is a need. When they were considering what to do they looked into Cedarcrest and the cost was her entire salary for the year. This is a really big issue that needs to be

solved. It is better solved at home morally and financially. Ms. James thanks the Commission for listening.

Ms. Gina Balkus introduces herself as the CEO of the Home Care Association of NH and advocacy affiliate Granite State Home Health Association. With Ms. Balkus is Ms. Sandra Poleatewich who is COO of Interim Health Care one of the large providers of private duty nursing care. Ms. Balkus states that they are there to present the home health agency perspective on what is a very serious issue. She begins by reviewing who Granite State Home Health Association is. They are a non-profit that represents 39 home care agencies licensed in NH. They provide advocacy and education on Home Health related issues. She states that a lot of what was discussed at this meeting was pediatric nursing but under Medicaid this is called private duty nursing. This is available to anyone of any age as long as they are eligible for Medicaid. So right from He-W 540 the definition of private duty nursing is skilled nursing services for recipients who require more individual and continual nursing, observation, judgment, assessment and interventions than available from a visiting nurse, in contrast to part-time or intermittent care, such as wound care. Visiting nurses are nurses that come once or twice a week for an hour or so to check on someone's condition or take care of a wound. Ms. Balkus continues that when they talk about private duty nursing it is continual nursing care and the rule states that it requires more than two (2) hours of nursing care at a time. The rule also states that the services that the nurses perform must be inherently complex or that the patient's condition requires services that can only be provided by a licensed nurse as opposed to a LNA or Personal Care Service Provider. Often in home care this is called "block nursing time". Often times in home care private duty is also known as self-pay. But in Medicaid this is private duty nursing Medicaid recipients who have the medical necessity for private duty nursing services are eligible. Today the discussion focuses on pediatric nursing but this is not just an issue involving children. Many clients are young adults that have aged up or adults with ALS. This is not just a pediatric issue. Ms. Balkus states that she did a survey two (2) weeks ago and currently, seven (7) Association members provide Medicaid Private Duty Nursing (PDN) services. Even though there are many more agencies in the state it is very specialized. There may be one or two others that are not part of their Association that provide these services. As of December 4, 2015 these agencies serve 104 patients for Medicaid PDN. Of these 104 patients, 32 patients are currently covered by MCOs: others will transition on February 1, 2016. There are 3,609 authorized hours of service each month with 769 hours (21%) unfilled due to lack of qualified staff. The reimbursement rate for agencies is \$41.80/hour for RN services and \$38.29/hour for LPN services. Reimbursement rates have not been updates since July 1, 2006.

Ms. Balkus turns the meeting over to Ms. Poleatewich to talk about the challenges that these agencies face in filling these hours. Ms. Poleatewich states that she has been doing this for many years and has seen more challenges in filling these hours over the past five (5) years. The rates that they get from Medicaid have to pay for the nurse's wages, unemployment, tax, training, education and this year they also had to pay for the employer mandate for health insurance. So when you look at all these costs the nurses get anywhere from \$21 to \$25 dollars per hour. Private Duty Nursing is ICU work in a home setting. Nurses must be qualified, competent and confident to work independently. Each new patient requires individualized training for the nurses. PDN is usually a per diem job. Hours cannot be guaranteed. If a patient is hospitalized the nurse does not work. The home/family dynamic can be stressful and wages are lower than other nursing positions. Other nursing jobs such as in hospitals offer better pay and less stress. We believe that these are the barriers along with technology. The other part of it is that there is a nursing shortage. But it is a special nurse that can work in home care. This is a very challenging environment to work in. Ms. Poleatewich concludes her presentation and asks if there are any questions.

Ms. Catherine Meinen comments that Ms. Poleatewich entire agency could not serve her daughter because of her daughter's weight. Ms. Poleatewich states that this is true because they have a policy of lifting up to 50 pounds and Zoe weighs 70 pounds. This is industry standard as a result of workers compensation.

Ms. Balkus states that the current low reimbursement limits the ability for home care agencies to recruit and retain private duty nurses. Reimbursement should be raised to \$58-60/hour for RNs and \$55-58/hour for LPNs care. If someone is authorized for 80 hours a week at \$41/hour the cost would be \$3,200. If the rate was raised to \$60/hour the cost would be \$4,800 per week. This seems like a big increase but when you factor in all the costs such as what happened to Lucas this week the cost of the medical intervention far exceeds the increase. There is also a false sense of network adequacy. MCOs currently contract with home care agencies that offer PDN care, however if agencies cannot cover all authorized hours, access to care is limited. When clients move to care management, rates will no longer be published as rates are confidentially negotiated between MCOs and providers. This limits the ability of families, providers and organizations to advocate for patients. Without meaningful increases to reimbursement, access to care for vulnerable patients will be compromised and patients will have no choice but to seek care in higher cost institutional settings.

Deputy Commissioner Marilee Nihan is introduced and states that she was going to do a presentation addressing NH's shortage in Pediatric Home Nursing however; she would like to be invited back next month to continue the conversation she states that this is an extremely important issue and the Department is very concerned and wants to resolve this. She thanks Ms. Heather Donnell and Ms. Audrey Gerkin for beginning the dialogue over the past couple of days. Deputy Commissioner Nihan states that the slide deck that she was going to give this afternoon will be on the Governor's and DHHS Webpages. DHHS priorities for the pediatric nursing shortage include chart reviews, wage scale and family reimbursement options, working with the NH Board of Nursing around issues outlined by Ms. Donnell and Ms. Gerkin and to also address licensing options. The top priority for the Department for the remainder of 2015 and 2016 is to take responsibility for this issue.

Ms. Jennifer Gertard, who has a daughter on the In Home Supports waiver states that in November her daughter's nurse, moved and they now have an open shift that they cannot fill. The workforce shortage is a national crisis.

Commissioner Wendy Gladstone thanks everyone and states that they have all learned a lot today.

Commissioner Mary Vallier-Kaplan thanks Commissioner Gladstone and states that this will be an agenda item for the future.

Commissioner Shumway thanks Commissioner Gladstone and Commissioner Fox who started this discussion as part of the Commission Network Adequacy and Services Workgroups.

Commissioner Vallier-Kaplan adjourns the meeting and 4:35PM and reminds the Commissioners of a special meeting on Monday December 14th on quality. Commissioner Porter will take notes and will provide the feedback in January.

Follow-Up Items

1. Commissioner Roberta Berner asks how many of the 131,000 rides were given by family or friends. Commissioner Toumpas responds that he will get that information for her.