Public Comments

Mississippi Division of Medicaid

State Plan Amendment 19-0023

Private Duty Nursing (PDN)

This is Rebecca Newman. I am the mother of a [redacted] old, tube fed [redacted] child with [redacted] disorder. We are able to benefit from PDN to allow for [redacted] to have safe, effective observation and intervention to allow him quality of life and to progress with motor learning. Our family relies on this service in order for each of us to work as well as to ensure his well being due to their highly skilled training.

It has been brought to our attention that your office is attempting to cut wages for our nursing staff that is so vital to [redacted] care. Because of them, he has avoided hospital stays and progression of illness complications since their starting.

On behalf of him and others like him, we urge you to avoid these cuts so that these children do not suffer and can avoid mounting costs of inpatient stays.

Thank you,
[redacted] and Rebecca Newman

09/09/19

Good afternoon, Margaret. My name is Heather Pennington. I do the billing for PediCare Staffing Agency, a PDN, company who provides care to children in the child's home. On Friday, a public noticed was put on the Division of Medicaid (DOM) site about PDN services.

On the DOM site, we were able to see the new fee schedule effective October 1, 2019. On the new listed fee schedule it does not show any fees with the appropriate modifiers (per current fee schedule **see attached**). I called the DOM today and spoke with Sonya. She informed me that effective October 1, 2019, there will no longer be modifiers to submit. She told me to send an email to you about this issue. A couple of our patients that we bill the S9123 (nursing care in the home, by a RN, per hour), have very complex health issues. We use the modifier TG (complex, high level care). These patients are ventilator dependent patients. Their care is complex. There is more work done by the RN, more documentation, etc. The way it is billed at this time with the modifier we use, we get a higher reimbursement for the work done. Can you please verify this to be correct? Will all modifiers pertaining to PDN services be done away with? Will only a flat rate of $32.41 be reimbursed no matter the patients complex medical care? Please advise?

We are so confused as to what is to come with PDN services and the reimbursement. If this is true and the DOM is doing away with all modifiers, this is unfortunate for everyone involved.

I appreciate your info on this matter.

Thanks,
Heather Pennington

09/09/19

Dear Margaret Wilson,

My name is Kristen South and I'm a RN for a Private Duty Nursing Facility. The pay cut Medicaid is trying to change will affect not only several hundred of our nursing jobs but also our babies and their families! Many of our children are not allowed to attend school, daycare, etc due to their condition. We take care of them at home so they would not have to live in the hospital and they require specialize nursing! We are paid $30 per hour and with this change we wouldn't be able to be paid 1/2 of that! Please please please really study and look at the effect this will cause tons of nurses and families!

Thanks,
Kristen S. South

09/09/19

To whom it may concern:

I am not sure if you are aware of what private duty nursing entails. Private nurses provide 8-24 hour a day in-home care to patients who would otherwise have to be in a hospital setting the majority of their lives. If this new plan passes you will be putting a lot of children's lives at risk. We provide care that parents aren't capable of providing due to the complexity, knowledge, and time it takes. You are jeopardizing innocent children's lives. As an RN I, nor most others, can't afford to work on these pay cuts. That means we will have to find other jobs as our private nursing companies continue to go out of business. Please please we urge you to reconsider this amendment. Please educate anyone and everyone who may not realize how important these companies and positions are.

With respect,
Brandi Foreman

09/09/19

Hi Margaret

I am the owner of Hope Healthcare. We care for just under 100 children in the state with special needs. Majority of our children have rare genetic disorders and disease processes that require very specialized care. Most of our RN babies have trachs, gtubes, immobility, non-verbal, immunocompromised, peritoneal dialysis...the list goes on and on. Some diagnoses that we care for are Genitopatellar syndrome, infantile pompe, CHAMPS, Turner syndrome, William's syndrome, Wolfhirshhorn syndrome, Cerebral Palsy, Congenital Nephrotic Syndrome...The list, again, goes on and on. There are studies being done in our state as well as nation wide on several of our children because of the severity and lack of knowledge of their disease processes. We cover the entire state with pediatric specialized nurses. I, by law, have to pay social security, payroll taxes, state taxes, federal taxes...(all of these equaling $70,000 every two weeks), 1/2 of each eligible employee's health insurance. I am also required to carry specific malpractice, general liability, worker's compensation by medicaid mandates. This does not include the cost of our physical office, supplies and administrative staff. I pay my RNs $30/hr minimum and LPNs $20/hr minimum. This reimbursement change will shut down every nursing agency in the state. Thus, leaving 100 babies, that we alone care for, with no nursing, and 300 nurses, that we alone employ, without a job. My biggest concern is these families that rely on us to have any type of normalcy in their life. The majority of our parents can not work to support their healthy family, let alone their chronically ill child's medical expenses. I am asking that this matter be reconsidered and this drastic cut be re-visited. Please feel free to contact me with any questions you may have regarding the care or patients that we proved care for.

Regards,

Amanda Brasel, RN, Owner
Hope Healthcare Staffing
o 769-524-3685
c 601-260-4190 (preferred)
f 601-510-8897
13252 I-55 Frontage Road South
Terry, MS 39170

09/09/19

As a caregiver of disabled children, I urge you not to proceed with these Medicaid cuts. Please don't take the much needed care these children deserve and the jobs these nurses need to care for their families.

Thank you,
Rachael Collier

09/09/19

Ms. Wilson,
My name is Vickie Embry. My son was born [redacted] with a severe congenital heart defect called [redacted]. He had [redacted] three days after birth, a tracheostomy, gtube and nissen on [redacted], and a second [redacted] on [redacted]. Due to his severe illness and suppressed immunity, he COULD not go anywhere, per the orders of his cardiologist and team, for the first year of his life. That would have meant my husband or I would have had to quit work and come home just to care for him and his daily needs. While that is exactly what we wanted to do, we could not afford to do so. We worried and prayed and made inquiries, and right before we were discharged, our care team told us about private duty nursing.

Private duty nursing has been a gift from the Lord to us. It allowed us to be able to work to financially benefit our family while still knowing that our precious boy was getting the proper care he needed. Hearing about the proposed Medicaid amendment, I felt the urgent need to contact this office to show both my concern and frankly, my outrage. Thousands upon thousands of dollars are wasted each year on things that are non-essential. People abuse the system and receive things they do not need for far longer than they need it. It is not policed or budgeted well. Now, to cover the shortfalls that those things create, it has been decided that a valuable service such as in home nursing care should be the scape goat. There are so many children who, like my son, cannot afford to leave their homes from mid-October to late April due to cold and flu. It would most likely shock these same individuals to see how much money is saved through the nursing care because hospital trips are avoided due the limited amount of exposure these fragile children have to have due to someone caring for them in the home. The children that qualify for this in home care cannot simply be "left with" anyone. They are all medically complex with devices that not everyone knows or can learn how to operate, fix or attend to. For example, when my son came home, he was on a home pulse oximeter 24 hours per day due to his trach, 24 hour continuous feeds via gtube due to double vocal cord paralysis from his heart surgery, had oxygen saturation levels in the 70's due to his heart defect and had to be constantly monitored for any airway obstruction or suction needed. I would not have left him with ANYONE other than my husband or a clinically trained nurse. This proposed amendment hurts working people like me who have medically complex children yet still have to work every day. Not to mention, the men and women who give up clinical nursing positions that pay more money and offer more benefits because they feel a call by the Lord to help care for these precious ones and to ease the burden their parents have will be penalized the most. They should not be punished due to budget short falls that were not created by them or their profession.

I strongly urge you to reconsider passing this amendment without taking into account the FULL bottom line of who is affected. Saving money is wonderful; however, when it comes at the expense of some of most fragile and vulnerable citizens, is it worth it? We, as parents and caregivers, will certainly fight this and do all we can to stand for those who cannot advocate for themselves. Please be a voice for the voiceless by fighting this amendment with us!

Thank you for your time,

Vickie

Vickie

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09/09/19

Hi Margaret,

My name is Jennie Rodgers, and my little boy battles with cerebral palsy.
His name is [redacted], and he is [redacted] old.
For the last many years, it is been just myself caring for [redacted] all day without any help.
[redacted] requires assistance with ALL activities of daily living. He depends on me for all of his needs (mainly God, but I am being used to help my precious boy).

Since June, we have been overly grateful for private duty nursing services that Medicaid has been paying for. A nurse comes to our home to help us every day during the week, which has taken a HUGE amount off of me - allowing him the extra care he so deserves.

We go through the company, Hope Healthcare. I was informed today that these services may not be able to continue if private duty nursing is cut by 40%.

Please please do what you can to stop this so that we can continue to receive these wonderful services.

I am attaching some pictures to put a face with his name.

Thank you, and I will be in prayer about this.

Jennie Rodgers
1624 East Main Street

09/09/19

Hello Mrs. Wilson,
I am emailing you in regard to the recently announced decreases in reimbursement rates for PDN. These drastic cuts (45%) will undoubtedly shut down every PDN company as well as leave hundreds of severely disabled Mississippi children without the vital in home nursing care that they require. The new reimbursement rates leave no revenue after nursing salaries to cover company expenses and overhead. The companies that provide this nursing care have to pay for taxes, administrators, managers, malpractice, worker's comp, software, etc. All in addition to paying nurses salaries. I urge anyone involved to please revisit these drastic changes as this affects disabled children, their families and the families that take care of them.

Thankyou,
Luke Brasel PA-C

09/09/19

Dear Mrs Wilson, I'm writing to you on behalf of my [redacted]. She benefits from PDN. She has severe seizure disorder and can have 10-20 seizures a day. She requires oxygen daily along with breathing treatments and is considered total care. It would be devastating to our family if she were to lose her nursing care. I can assure you there would be a huge increased cost for hospital care as she would be sick if sent to a care facility daily because she was always sick prior to having PDN. This not only affects the lives of these kids but the family as well. As we would have to find jobs and unqualified people to keep her so we could work. I'm begging that you do whatever is in your power to keep PDN for all these babies that deserve quality care in their own homes.

Warmest Regards,
Mother to [redacted]
Cameron

09/09/19

Mrs. Wilson,
I'm writing you as a concerned citizen to say that these cuts will tremendously hurt the care that so many parents with special needs children depend on. This has enabled most parents to have some relief involving the 24 hour care most need. These cuts would drastically reduce the amount of hours available for nurses to give children. I hope and pray these cuts are voted down and the special needs children are taken care of like they should be. Thank you for your time.

John Coates
Good Hope Inc.
P.O. Box 614
Natchez, MS 39121
601-431-5663
john@g-hope.com
www.g-hope.com

09/09/19

To whom it may concern:

I'm asking that you reconsider cutting nursing reimbursement for medically fragile children. I work as an RN for an agency that provides palliative pediatric care. It's my only job. My patient is [redacted] and I've been working with her since she was [redacted] old. She is ventilator dependent. Her condition is so complex that a care giver is confined to the room with her 24 hours a day. She is hook up to 3 different machines 24/7. There are days when the mom doesn't have nursing care at all and it is extremely difficult for her. Her mom cares for two other children as well. A 40% percent cut is very sudden and extreme. Please consider the families that this will affect. If this child doesn't have nursing care her hospital stays will definitely be numerous. She has not been in hospitalized since [redacted]. Her condition requires constant care. Please don't pass this.

Thank you for your time,
Joni Bryant

09/09/19

Good Afternoon,

On behalf of my family and the patients I serve through PDN care, I ask that the deduction in cost not be followed through & that no deductions be made.

If these were to officially be implemented, it would burden the nurses that care for these patients by a decrease in income (by a significant amount) as well as a decrease in care for the families we serve. These families need us-and if they lose nursing, there could be an influx of ER/Hospital visits due to lack of private nursing care.
Again, we ask that the Division of Medicaid reconsider this decrease of funding.

Thank you
Jamie Elam, LPN

09/09/19

What other places are funds being cut? How will the funds being taken from PDN care be appropriated? How much of the % of that will be cut from PDN care?

Thanks,
Jamie Elam, LPN

09/09/19

My [redacted] and severely disabled with a Neurological condition. He is nonverbal, history of seizures, wheelchair bound and is fed with a gastrostomy tube. He is also on a ventilator at night for his severe apnea. Within the past year we finally discovered that we were eligible for private nursing assistance through Medicaid. We began getting a night nurse and it was a game changer for us. For the first time in 13 years we were able to sleep for an entire night without having to get up and take care of him multiple times. In addition, these services help tremendously caring for [redacted] in other day to day areas as he gets older and heavier.

I just received notice that there are significant cuts to this program being implemented effective Oct 1 2019, and our nursing company will not be able to stay afloat and cover their overhead under these new guidelines. I urge you to reconsider this policy and please realize that this is not just another budget item, these are real kids with real needs.

Thank you,
Neal Coay
509 Camden Ct
Brandon MS 39047

09/09/19

I am the grandmother of a special needs [redacted]. [redacted] has [redacted] [redacted] [redacted] and [redacted] [redacted]. she is the only person in the world to have both of these syndromes at the same time and due to the complexity of [redacted] illness it requires a team of nurses to care for [redacted] while my single daughter tries to work to support [redacted] and her other children. Please do not cut the funds for these nurses, so many children besides my [redacted] and thier families require the help of these RN's that LPN are not trained to do. Thank you for your time and I hope you will not cut this funding.

09/09/19

To Whom it May Concern:

I am writing in regard to the public notice on 42 C.F.R. Section 447.205 addressing the proposed reduction in spending and allowances to private duty nursing. It is of paramount interest to me because I am a private duty RN who has been in service to those with disabilities under the age of 19 in the state of Mississippi for four years. This issue directly impacts my patient's livelihood and safety and it is imperative that the amendment not move forward.

I have been doing my job for over four years now, and I have witnessed God's hands work numerous times. The one thing I have seen the most of in my managerial role with homebound children is the parents say over and over again how much nursing has impacted their lives in positive ways. The most rewarding part of my job is seeing a child, who is expected to leave the world, live for months and years longer than expected because of the detailed level of care they receive at home. Although some see it as an added expense, the reality of it is that nursing helps to increase the lifespan and normalcy of a child born with diseases that were out of their control.

As a tax paying citizen and public servant in the healthcare field, I demand that at home nursing be left alone contrary to the expected agenda of cutting funds. One does not really understand what takes place until they have their own special needs child or has served a family with a child that has extra needs. Allowing in home nursing helps to ensure that the children are receiving optimal care at all times which helps to save money on hospitalizations and avoidable machines and medicines. In home nursing services also allows families to continue to work and be productive members of society which helps the state and country as a whole with the financial burden that is placed on us to pay for others who do not and cannot work to pay for themselves.

Thank you for your consideration of my viewpoint on this matter. I believe it is an important issue and would like to see this change FAIL to move forward to help ensure effective healthcare services be given to those who did not choose the diseases they are faced with. I look forward to a timely response with a detailed summary of your views on the situation.

Sincerely,
Lesley Hudson Pegg, BSN

09/09/19

My family has been made aware of Medicaid's decision to reduce reimbursement for private duty nursing. My family is directly effected by this as we receive nursing care for our [redacted] with a neuromuscular disease and our [redacted] w Down syndrome and autism. These children and these families rely on this cate to be able to function. This is what Medicaid is for. Please reconsider.

09/09/19

To Whom It May Concern,

My name is Raven Johnson. My daughter [redacted] receives Private Duty Nursing by registered nurses due to her severe medical conditions. I want you to understand that cutting the reimbursement pay will in turn cause nursing companies to cut pay and hours for children like my daughter. I am a single mother of 3 children. I work a full time job. My nurses care for and help keep my daughter alive while I attempt to make a living for me and my family. If there is a cut, my nurses would not be able to afford to work and help care for my daughter anymore. In turn, I will not be able to work and support my family because I will have to stay home to care for my child who requires full time care. Please reconsider this decision as it will hurt my family and hundreds of other families like mine. Enclosed is a picture of my daughter. As you can see from the picture, my child has a tracheotomy, a GJ tube, a ventilator, a colostomy, and A lot of other equipment due to her severe medical conditions.

Thank you for your time,
Raven Johnson

09/09/19

We respectfully ask that you reconsider! Our family has two special needs children ([redacted]) that are directly affected by this change. It has made the situation so much more "doable" and we are no sure how they will manage if this wonderful service is removed. Please reconsider!

Linda Huff

09/09/19

Good Morning Miss Wilson

I am writing you with pain staking feeling in my heart.
I just found out through my Daughter, [redacted] that there will be a 40% decrease in private duty nursing reimbursements across the great state of Mississippi.

There are hundreds and even thousands of families across Mississippi that this will definably hurt.

My Grandson, [redacted] has a sever medical condition, Cerebral Palsy. [redacted] was born with this condition.
[redacted] needs help 24 hours a day. [redacted] takes care of him with the outside help of the private duty nursing.

I am asking you to please work with Mississippi Senators and government to stop this from happening on behalf of all the families that need this.
I am a tax payer, been one for over 40 years and I believe this is a great use of our tax dollars.

Thank You

Henry Pate
henrypate@att.net

09/10/19

"Dear Ms. Wilson,

You don't know me but I wanted to write you to inform you that private nurses are needed for a rather large number of home bound patients. Many of theses nurses will be cut due to the compensation rate will be dramatically reduced. These private nurses who work for these families will have to seek employment elsewhere due the the reduced compensation.

One such family is that of my homebound student [redacted]. He has [redacted]. [redacted] has left him bed bound, trach and vent dependent, reliant on tube feedings and round the clock care. When [redacted] was diagnosed the doctors told his family that he wouldn't make it to two years old. Well here hes is three beautifully and miraculous years later. His mother and father,both work and rely on a nurse to help provide a high level of care for their medically complex child. [redacted] needs these nurses to survive. His parents need these nurses to survive. With out the help of these private nurses, [redacted] (his mother and father) would loss sleep, not be able to eat a warm meal, shower or anything to keep themselves healthy due to constantly having to focus on [redacted]. Since [redacted] is trach and vent dependent, he has to have suction to help keep spit and mucus from going to his lungs. Trach care is vital to [redacted] health and well being. It takes a trained nurse to care for his trach and vent needs. [redacted] love their son more than words but due to his complexity they need help. They would miss out on all the mile stones their other child meets. Without a nurse their youngest child will miss out on a somewhat normal child hood due to helping her parents care for her brother.

[redacted] has therapies several times a week and [redacted] has to have help to get him to the therapies while she is at work, providing for her family.

I ask you to please reconsider cutting the compensation for these nurses as they are vital to those who they care for. These nurses are so much more than caregivers, they are family, best friends, comforters and most of all they are the biggest advocates for their patients next to the patients parents or family. I have seen first hand how much [redacted] nurses help him and his family out. I urge you to think if this was once of your family members would you be ok with compensation being cut for their nursing care?

I thank you for your consideration in this matter. "

Teresa Rials

09/10/19

Ms. Wilson,

I would like to introduce you to my son, [redacted] (photo attached). He is a sweet [redacted] who was born with a rare congenital heart defect called [redacted]. This means that the "plumbing" of his heart is not connected properly, so his heart is unable to pump oxygenated blood to his body. At [redacted], he underwent a balloon atrial septostomy, a catheter based procedure, and at [redacted] he underwent surgery to place a BT shunt. These procedures allow mixing of oxygenated blood and have increased his oxygen saturation to 80% (a normal person has an oxygen saturation of 100%). This was done to buy him time to grow big enough to undergo open heart surgery to repair his heart.

Because of [redacted] tenuous, shunt-dependent circulation, he qualifies for the Disabled Child Living at Home provision of Medicaid and qualifies for Private Duty Nursing. The slightest cold will land him in the hospital and is potentially life threatening, so [redacted] cardiologist will not allow him to attend daycare. Having a nurse come to our home allows my husband and me to continue working and to care for our other child. It has been such a blessing for our family and has been a lifeline in the wake of [redacted] devastating diagnosis. Caring for a sick child is physically, emotionally, and financially taxing, and we rely on private duty nursing to help us through this difficult time, as do many families with sick children.

I urge you to reconsider cutting nursing reimbursement as laid out in Medicaid State Plan Amendment 19-0023. Children and families like ours will suffer as a result of the cut in reimbursement.

Thank you,
Megan Cretella

09/10/19

There are plenty of families who need nursing care from Medicaid, and there will not be a possibility for agencies to provide this care if there is a large pay cut. I am a nurse who works frequently to change the life of these patients and families. Please do not cut funding. We need our jobs, and these families need to be able to provide for their own families. With a pay cut, this would not happen and these families will be at home caring for their special needs children rather than working outside of the home. The children aren't a burden, but the parents deserve some peace of mind along with independence for themselves! Please do not cut Medicaid funding!

Sherry Harper RN, PSN

09/10/19

To whom it may concern,

I am a private duty nurse in the Jackson area. I have served our children for almost 2 years now, and I love what I do. The recent news has truly devastated me and my families I work with. I work anywhere from 8 to 16 hour shifts, and a lot of times I stay overnight so the parents can finally sleep. These children are so fragile. Just because they are home doesn't mean they don't need hospital level care, and we are trained to provide that and more. Everything done in a hospital can be done in the home by a private duty nurse, except there is way more stress on us because we do not have a doctor we can call. I've worked with everything you can imagine. Coming from someone who sees and knows how vulnerable these children are to getting sick and furthermore hospitalized, I am pleading that you not decrease our funding. Simply put, decreasing funding will decrease nursing care (not to mention will leave many unemployed, not just nurses but the parents who now have to quit their jobs to come home), and without nursing expertise in the home, children WILL be hospitalized, and because they are on Medicaid, the money to pay these bills will come from the same pot where private duty nurses could have been paid to prevent this. Please consider all the people writing, emailing, calling. I have become like family to my patients, and I can't imagine losing this due to a massive decrease in our funding.

Thank you for your time

Elise Ades, RN

09/10/19

To whom it may concern,

It has come to my attention today that the Division of Medicaid is cutting reimbursement for private duty nursing by 40%. I am writing to ask anyone who will listen to reconsider this decision. This decision has a direct affect on my family. One of my nieces is [redacted] living with [redacted]. If you are not familiar with this diagnosis, it is probably because it is quite rare. An adult diagnosis that you are likely much more familiar with is ALS. SMA is basically a pediatric, congenital version of ALS. It is a degenerative wasting of muscles throughout the entire body for which there is no cure. My niece is dependent on a specialized power wheelchair in order to independently move herself around in her home, school and community environment. While the use of assistive technology greatly enhances her ability to mobilize herself, she is unable to transfer herself, bathe herself, perform toileting herself, manage her respiratory insufficiency, mange her skin health and prevention of pressure ulcers, etc. She is dependent on private duty nursing for assistance with these aspects and many other aspects of her self care. She is one of 3 special needs children in her family of 7. One of her sisters, has Down's syndrome and autism, and also utilizes private duty nursing services. These are necessary services that allow my brother in law and sister in law to provide appropriate medical care for their medically complex children. Without these services covered by their Medicaid benefits, they would be responsible for paying for this expensive service out of their pockets. This would be extremely cost prohibitive for them and would impact the level of care my nieces could receive and would directly negatively impact their quality of life.

While this decision affects my family directly, it also affects many of the clients that I work with in my job as a Physical Therapist and Seating and Mobility Specialist at Methodist Rehabilitation Center. All of the clients I serve are living with some form of physical disability including conditions such as spinal cord injury, brain injury, cerebral palsy, spina bifida, [redacted] and many others. Many of these individuals rely on private duty nursing services to manage their medical needs. These are services that they could not pay for without assistance from the Division of Medicaid. PLEASE, for the sake of my precious nieces and many of the special clients that I work with, reconsider the decision to cut reimbursement for private duty nursing!

Sincerely,
Cameron Huff

09/10/19

"Dear Ms. Wilson,

You don't know me but I wanted to write you to inform you that private nurses are needed for a rather large number of home bound patients. Many of theses nurses will be cut due to the compensation rate will be dramatically reduced. These private nurses who work for these families will have to seek employment elsewhere due the the reduced compensation.

One such family is that of my own cousin, [redacted] [redacted]. He has [redacted]). [redacted] has left him bed bound, trach and vent dependent, reliant on tube feedings and round the clock care. When [redacted] was diagnosed the doctors told his family that he wouldn't make it to two years old. Well here hes is three beautifully and miraculous years later. His mother and father, who is my cousin, both work and rely on a nurse to help provide a high level of care for their medically complex child. [redacted] needs these nurses to survive. His parents need these nurses to survive. With out the help of these private nurses, [redacted] (his mother and father) would loss sleep, not be able to eat a warm meal, shower or anything to keep themselves healthy due to constantly having to focus on [redacted]. Since [redacted] is trach and vent dependent, he has to have suction to help keep spit and mucus from going to his lungs. Trach care is vital to [redacted] health and well being. It takes a trained nurse to care for his trach and vent needs. [redacted] love their son more than words but due to his complexity they need help. They would miss out on all the mile stones their other child meets. Without a nurse their youngest child will miss out on a somewhat normal child hood due to helping her parents care for her brother. [redacted] has therapies several times a week and [redacted] has to have help to get him to the therapies while she is at work, providing for her family.

I ask you to please reconsider cutting the compensation for these nurses as they are vital to those who they care for. These nurses are so much more than caregivers, they are family, best friends, comforters and most of all they are the biggest advocates for their patients next to the patients parents or family. I have seen first hand how much [redacted] nurses help him and his family out. I urge you to think if this was once of your family members would you be ok with compensation being cut for their nursing care?

I thank you for your consideration in this matter. "

Michelle Cook

09/10/19

Good Morning,

My name is Melissa Cook and I'm a private duty nurse. I love my job and I feel like I was led by God to care for these babies. I would like to take a minute to educate you on just one of our patients. He is a three year old little boy with a rare genetic disease called spinal muscular atrophy. He has a father, mother, and a little sister that love him very much. As well as the rest of his family and his nurses. He has fought to stay alive and thrive every day of his life. He is happy, he laughs and smiles and plays. We keep him healthy. He can only breathe with help from a ventilator. He has a tracheotomy to breathe and a g-tube to eat. He loves to pull his vent tube off every few minutes! His parents are not rich, they live paycheck to paycheck. His mom works two jobs. If they lose nursing care she will not be able to work. It will take everything she can just to take care of him alone. He will get sick and be hospitalized at least two times a year. With an average hospital bill of $70,000. He will probably not make it for long.

He is just one of hundreds of babies that desperately need our help. Their families need our help. We keep these babies out of the hospital. Hospitalization rates will drastically increase without private duty nurses which will in turn cost Medicaid millions. Hundreds of nurses will be out work, like myself. I have 8 children of my own to take care of.

I wish that you all could see the affect that these cuts will make on us all. You all see money saved, we see lives lost, families suffering, and sickness taking over our babies that we love so much.

Melissa Cook

09/10/19

Please donot cut the money for home nursing! I have a special needs Neice that would be completely home bound without the help of her home Nurse. She wouldn't be able to get to her Doctor appointments or even out the front door without the help of her home Nurse. My Sister has to have help and her home nurse is a vital part of every day life for my Neice. Please donot do this! We need our home Nurse. Thank you!

09/10/19

My name is Kate Taylor and I am the owner of Faith and Friends Healthcare Staffing, a private duty nursing agency that provides care to medically complex children. I am disheartened by the suggested fee schedule change for several reasons that I'd like you to consider:

1. As a small business owner trying to grow my business, by
   cutting the reimbursement rate and not allowing differential pay through medical modifiers (specifically the TG modifier) I will not be able to grow let alone sustain my business and continue to pay my nurses what I currently pay them. I understand Medicaid used the Federal Labor Law statistics on the average salary for nurses in the state of Mississippi. I think this is a misrepresentation of what PDN companies pay in order to provide individualized care. There are many factors being left out when you just consider an "average" pay scale.
   For instance, training, level of expertise and ability to care for and maintain life sustaining equipment for medically fragile children.
   Most nurses that are willing to go into homes of children with complex needs are highly trained and qualified to handle medical emergencies and provide life saving measures as needed. You cannot compare this level of skilled nursing and expect to find RN's willing to do this job for a wage that is not even based on local paying nursing job. You are also not considering that some agencies pay differential and holiday pay to secure coverage for our patients. At the suggested reimbursement rate, nurses in the local Jackson metropolitan area would be better off to work at the hospital and receive insurance and retirement benefits and differential pay based on

shifts and years of experience than to work for a PDN company. Ultimately because of this, children and the families of kids with special needs will suffer.

2. New regulations require me to staff a nurse supervisor that does not have patient care. This salary will be paid from what Medicaid has considered "administrative" costs. However, if we continue to pay our nurses what they are accustomed to, the administrative costs do not cover the monthly cost of business let alone a nurse supervisor. Medicaid requires companies to have a business location and complete background checks. Also, in order to accurately and efficiently keep track of nurse timecards and payments, software needs to be utilized which incurs another monthly expense.
   Medicaid has not accounted for the business owner's expenses when cutting the reimbursement fee so significantly. This is not including taxes, insurance or a living wage for the business owner. Also not considered are expenses such as marketing, recruitment, advertising costs, incentive pay and holiday pay for nurses. Can cutbacks be made?
   Certainly. Should they be cutback 36.5% at the expense of saving money for the state and drastically diminishing the ability to provide quality nursing care for medically complex kids? Absolutely not!

3. Medicaid changing this reimbursement rate so that all RN care is the same is not accounting for the differences in these medically complex kids. Each child is completely different on the medical spectrum. For example, a client that has a tracheotomy, a g-tube and requires ventilator assistance and cannot walk and talk and requires intensive therapy each and every day needs nurses that must be highly trained in order to care for her extensive needs and in order to correctly and confidently know how to utilize her equipment. This is very different from other kids that need nursing care for less life threatening and life-limiting diagnoses. The nurses liability for taking care of the above mentioned client is substantially higher than that of a nurse at a clinic. To say that this client is the same as all kids that need nursing and not seeing that she is more complex is a massive oversight and a potentially dangerous situation. As a mother of 3 children, I expect the school system to differentiate their teaching to accommodate my children's learning styles and provide an individualized education plan for my son that requires it. I see no difference in my client's rights to receiving individualized care at the level they need it and for the state to be able to differentiate pay reimbursement rates for these higher needs children.

4. The new reimbursement rate is a 36.5% decrease. Any business owner that incurs a reduction so great will go out of business quickly and leave these precious children without care.

Please consider changing the ability to reimburse modifiers for PDN companies so that we can run our business in a way that provides the HIGHEST quality of care for children who need private duty nurses to achieve their best quality of life and to enhance the lives of their families as well.

Respectfully yours,

Kate Taylor

09/10/19

"Dear Ms. Wilson,

You don't know me but I wanted to write you to inform you that private nurses are needed for a rather large number of home bound patients. Many of theses nurses will be cut due to the compensation rate will be dramatically reduced. These private nurses who work for these families will have to seek employment elsewhere due the the reduced compensation.

One such family is that of my own cousin, [redacted]. He has [redacted]). [redacted] has left him bed bound, trach and vent dependent, reliant on tube feedings and round the clock care. When [redacted] was diagnosed the doctors told his family that he wouldn't make it to two years old. Well here hes is three beautifully and miraculous years later. His mother and father, who is my cousin, both work and rely on a nurse to help provide a high level of care for their medically complex child. [redacted] needs these nurses to survive. His parents need these nurses to survive. With out the help of these private nurses, [redacted] (his mother and father) would loss sleep, not be able to eat a warm meal, shower or anything to keep themselves healthy due to constantly having to focus on [redacted]. Since [redacted] is trach and vent dependent, he has to have suction to help keep spit and mucus from going to his lungs. Trach care is vital to [redacted] health and well being. It takes a trained nurse to care for his trach and vent needs. [redacted] love their son more than words but due to his complexity they need help. They would miss out on all the mile stones their other child meets. Without a nurse their youngest child will miss out on a somewhat normal child hood due to helping her parents care for her brother. [redacted] has therapies several times a week and [redacted] has to have help to get him to the therapies while she is at work, providing for her family.

I ask you to please reconsider cutting the compensation for these nurses as they are vital to those who they care for. These nurses are so much more than caregivers, they are family, best friends, comforters and most of all they are the biggest advocates for their patients next to the patients parents or family. I have seen first hand how much [redacted] nurses help him and his family out. I urge you to think if this was once of your family members would you be ok with compensation being cut for their nursing care?

I thank you for your consideration in this matter.

Kasey Boswell

09/10/19

"Dear Ms. Wilson,

You don't know me but I wanted to write you to inform you that private nurses are needed for a rather large number of home bound patients. Many of theses nurses will be cut due to the compensation rate will be dramatically reduced. These private nurses who work for these families will have to seek employment elsewhere due the the reduced compensation.

One such family is that of my own cousin, [redacted]. He has [redacted]). [redacted] has left him bed bound, trach and vent dependent, reliant on tube feedings and round the clock care. When [redacted] was diagnosed the doctors told his family that he wouldn't make it to two years old. Well here hes is three beautifully and miraculous years later. His mother and father, who is my cousin, both work and rely on a nurse to help provide a high level of care for their medically complex child. [redacted] needs these nurses to survive. His parents need these nurses to survive. With out the help of these private nurses, [redacted] (his mother and father) would loss sleep, not be able to eat a warm meal, shower or anything to keep themselves healthy due to constantly having to focus on [redacted]. Since [redacted] is trach and vent dependent, he has to have suction to help keep spit and mucus from going to his lungs. Trach care is vital to [redacted] health and well being. It takes a trained nurse to care for his trach and vent needs. [redacted] love their son more than words but due to his complexity they need help. They would miss out on all the mile stones their other child meets. Without a nurse their youngest child will miss out on a somewhat normal child hood due to helping her parents care for her brother. [redacted] has therapies several times a week and [redacted] has to have help to get him to the therapies while she is at work, providing for her family.

I ask you to please reconsider cutting the compensation for these nurses as they are vital to those who they care for. These nurses are so much more than caregivers, they are family, best friends, comforters and most of all they are the biggest advocates for their patients next to the patients parents or family. I have seen first hand how much [redacted] nurses help him and his family out. I urge you to think if this was once of your family members would you be ok with compensation being cut for their nursing care?

I thank you for your consideration in this matter. "

Clair Miller

09/10/19

Dear Ms. Wilson,

You don't know me but I wanted to let you know that without Medicaid helping with home bound terminal ill patients, many of the families will not be able to afford a nurse! Many of them really need that help!

Such as my step grandson , [redacted]. He has [redacted]). [redacted] has left him bed bound, trach and vent dependent, reliant on tube feedings and round the clock care. When [redacted] was diagnosed the doctors told his family that he wouldn't make it to two years old. Well here hes is three beautifully and miraculous years later. His mother and father rely on a nurse to help provide a high level of care for their medically complex child. [redacted] needs these nurses to survive. His parents need these nurses to survive. [redacted] has therapies several times a week and [redacted] has to have help to get him to the therapies while she is at work, providing for her family.

I ask you to please reconsider cutting the compensation for these nurses as they are vital to those who they care for. These nurses are so much more than caregivers, they are family, best friends, comforters and most of all they are the biggest advocates for their patients next to the patients parents or family. I have seen first hand how much [redacted] nurses help him and his family out. I urge you to think if this was once of your family members would you be ok with compensation being cut for their nursing care?

Jennifer Sumrall

09/10/19

My grandson who is [redacted], has [redacted] he was diagnosed at [redacted] only given 2 maybe 3 years to live. He has a ventilator to breath, a G-tube (gastrostomy tube) to eat, he has physical therapy come to his home 3 times a week and he's now about to start [redacted] at home.

I live in [redacted] and recently got to see [redacted] for his birthday we went to eat with everyone and I sat with [redacted] at the restaurant and it took me 3xs as long to eat as normal between suctioning, him replacing his vent, because he likes to pull it off and checking every 2-3 minutes to see why his oxygen alarm was going off.

As a certified medical assistant here at home, I know first hand if you cut the funding there is going to be so many families that are going to be going from a hard time to a devastating time.

Because, of the private duty nursing [redacted] mom and dad get to sleep and will not have to care for him sleep deprived, they can both work to keep their home and keep food on the table.

Without their (Guardian Angel) nurses families who need them will be put into situations where life will be impossible.

No sleep, no money cause it takes two to work just to survive.

Please go visit and spend a day with a family who needs a private nurse then decide about cutting the money!

April White

09/10/19

I would like to take a minute to express my concerns on the potential cutbacks for in home nursing. I have a nephew that has in home nursing and with them I am not sure what his parents would do!! Having the nurses to help care for him has kept him out of the hospital on several occasions. With them being able to more closely monitor his day to day stats have allowed them and his parents to get in front of possible sicknesses that may have occurred if they had not been there. These nurses are SO important to these families in so many ways. Having the nurses here helps the family medically but also it provides a way for families to still provide for their families by being able to work. When the nurses are able to help care for the child at home it keeps the patients at home instead of having them in an environment where they could potentially become more sick. I feel that there are so many other ways to make cuts in the medical field instead of taking away from the patients that are in true need of it. Please take a moment to reconsider these cutbacks and how devastating it will be for the patients and their families.

Christina Shepard
Materials Analyst III
601-479-7074 Cell
601-678-4090 Office

09/10/19

Margaret,

I am writing you about the two changes that are being implemented on October 1, 2019:

Medicaid State Plan Amendment (SPA) 19-0002 Prescribed Pediatric Extended Care Center (PPEC)
Medicaid State Plan Amendment (SPA) 19-0023 Private Duty Nursing (PDN)

These cuts are very drastic and what I have been told by my PDN company is they will close their doors due to the loss. I am having a hard time understanding why you would cut something so drastically that it would remove care from medically fragile children and force parents to stay at home to care for the child vs. earning a living, paying taxes, and spending money in local businesses. Some parents don't have the skills/education to care for these children due to their complexity. So you are putting their lives at risk.

How was this cut originated? Who studied this? Did anyone with a nursing background participate in fact finding? What about someone with a business degree? Did you utilize someone skill in performance improvement? CMS has an entire division dedicated to performance improvement (Center for Transforming Healthcare). Its a top priority for them, is it for The Division of Medicaid of Mississippi? Or did the team just shoot from the hip since this doesn't effect them personally?

I see we are saving federal dollars not state, did we have state representation on this fact finding effort?

Did you consider saving these federal dollars elsewhere before taking care away from innocent children?

How long have you known about these changes? Who approves these changes?

Is there a plan for these children as they are losing their private duty nursing and potentially daycare (PPEC)? Will you be available to care for my child and do you have the skills required to do so?

Are there more cuts coming in the future the medically fragile children?

I have many more questions so please contact me as soon as possible,

Rachel Guy
601.842.0906
rebrock22@hotmail.com

09/10/19

Hello Margaret,

I am writing on behalf of [redacted] in [redacted], MS and on behalf of the nurses who care for him. He is a [redacted] child born with Cerebral Palsy and a recipient of private duty nursing. I am told the rate of reimbursement will possibly decrease by 40% beginning October 1st, 2019. This will cause a lack of skilled nurses to be able to care for him. This will cause the families to have 40% MORE stress, and 40% less time to do those activities of daily life that allow them to care for their loved one during the majority of times without any assistance. This will greatly impact the families of those who have already been dealt so many extra challenges in life. Please reconsider the families when you are making decisions regarding the reimbursement of private duty nurses. The ones who need funding and assistance the most are NOT the ones that need a 40% decrease in financial assistance. There are too many other options in budget cuts than to take from your state's weakest and most vulnerable. As Mississippians, as Americans, as human beings, as Christians, we are obligated to take care of the weak.

"The King will reply, 'I tell you the truth, whatever you did for one of the least of these brothers of mine, you did for me.'
Matthew 25:40.

Thank you,
Melissa R. Nolan FNP-C

09/10/19

Ms. Wilson,

It has come to my attention that Mississippi Medicaid is cutting RN and LPN reimbursement for private duty nursing care. This is a grave disservice to patients of Mississippi. I am currently a part-time contracted pediatric private duty nurse, and my patients have complex medical care that require one on one nursing care with the expertise of registered nurse. I am a full-time employee in a pediatric critical care unit, so I have seen first hand the consequences of poor nursing care at home and in PPEC facilities. If these patients do not receive adequate nursing care at home, it will very likely lead to hospital admissions, which in turn would accrue inpatient bills that would far surpass the pay for quality nursing coverage at home. In addition to effecting quality nursing care, it will put private duty nursing businesses in jeopardy. This will result in decreased rates of patient/family satisfaction, an increase of sentinel events in the home setting, and the loss of hope in a healthcare system designed to protect our patients. I urge you to reconsider the decision to cut nursing reimbursement for private duty healthcare. Not all patients are the same. Complex care patients deserve premier nursing care, and quality nursing is the leader in positive patient experience. This decision will reflect poorly on Mississippi Medicaid's care of the patients it is supposed to protect.

Sincerely,

Abigail Collins, BSN, RN, CCRN-P

09/10/19

Dear Ms Wilson,

I just heard they might cut the pay for LPN nurses for those who work for medicaid home care patients.

Please don't allow this as it is already very difficult to get enough care for those families that really need it to survive and take care of there loved ones. If there is a pay cut there will never be enough nurses willing to take care of these patients.

Thank you!
Susie Grothe

09/10/19

Mrs. Wilson,

I am extremely blessed to be chosen by God to be mama to a special needs little miracle who receives private duty nursing in our home. My child has multiple chronic diagnosis. She is tube fed, oxygen dependent, non ambulatory and non verbal. I received notice yesterday of the plan of amendment for private duty nursing. I beg you to view this from a different aspect. As a mother, private duty nursing is a huge blessing to us. Without this service, my child could not even go to her Dr appointments or therapy appointments because I can no longer get her in the vehicle unassisted. Because of private duty nursing, I am a better mama to both of my children. I can do things that are important such as get medication refills, clean house, get some much needed rest, buy groceries, take a bath and wash my hair. Things that most people take for granted. Without this service, I cannot do these things because my child could have a seizure and stop breathing, she could fall or choke to death. She has to be watched 24 hrs a day. I get 56 hours a week nursing care for my child. That equals up to 2 1/2 days. That's all. If we lose this service or if this service is cut, more families will have to make the decision to institutionalize their child and some will have to quit their jobs and be forced to seek government assistance for Medicaid for the family and food stamps. Some will be forced to live in the children's hospital to receive lifesaving care. I understand that cuts have to be made, but this is not the place to make the cut. It would end up being financial suicide for the state and would ultimately cost some of Mississippi's most precious and innocent citizens their life and quality of life. Private duty nursing is essential to quality of life for my family and many other special needs families. Thank you for your consideration in this matter.

Monica David

John 16:33

09/10/19

Hi,

Please do not cut lpn pay for those caring for Medicaid patients. I have a dear friend that has a special needs child that receives night care and if she loses that care she will not be able to continue on with her own lpn degree and get back on her feet after a nasty divorce. It not only affects the nurses lives , it affects such a larger scale for the families those nurses care for.

Thank you for taking time to read this.

Cheryl Lauderdale

09/10/19

Good afternoon, my name is Dorothy R. Meeks. Yesterday I was awake by disturbing news from my employer. About a bill that's in your hands to sign. Before you sign please consider the lives you will affect. Beware we only have the Supper Rich and poor and supper poor. There's no more middle class. It's hard enough to pay rent / mortgage, car & health insurance and keep food on my table. This bill will cause even more stress & stains on life. Thank you for your time.

Sent from [redacted]
Mrs Dorothy R. Meeks

09/10/19

Mrs. Wilson,

I urge you to reconsider the ruling for SPA 19-0023. There a number of children that need special assistance that will not be able to receive it if this goes into effect. These are children who need assistance. Children who cannot do for themselves. Children who without medical assistance would not thrive. Children who without medical assistance would not live the best life they can. These are not grown adults who can help themselves. These are babies, toddlers, children who are completely reliant on their caretakers.

I am pleading with you to reconsider SPA 19-0023.

Sincerely,

Kristen Dendis

09/10/19

Dear Ms. Wilson, It has come to my attention that cutting the pay for LPN nurses who do home care for Medicaid patients is currently under consideration. I would like to strongly ask that you not only not cut their pay, but consider the fact that these nurses have not had a pay increase for the last twenty years. To cut the pay of these nurses could cause a mass exodus of these valuable professionals from home care work. Many patients and their families and their health will be put in danger because of this decision. I work with one young man on Sunday mornings at our church. To lose the care she provides during the evening hours would mean putting not only his very life in jeopardy, but would have a ripple effect on the entire family. In addition, it has been the valued LPNs who have helped us during the care of a family member with Alzheimers. Without them, we would have crumbled under the weight. To think that their salary is going to be cut is not only unfair, but undeserved considering the value they offer their patients and their families. To all of us, they are unsung heroes.I realize that budgets are tight and things have to be done, but please do not make those working hardest suffer. If you can't give them a raise, do not cut their pay. Thank you for your time, consideration and attention.

Deanna Germany
Case Manager, Madison and Rankin Adult Court
Academic Case Manager, MCJ4Y

t: 601-201-7031
e: ldgermany@outlook.com

Twentieth District Circuit Court

www.mcjobs4youth.com

09/10/19

Mrs. Wilson,

I am an RN that provides private duty nursing care to a medically complex child. My patient has multiple diagnosis, with her main diagnosis being Mitochondrial disease. She is completely pacemaker dependent, non verbal, and non ambulatory. She requires tube feedings and constant watch due to uncontrolled seizures. Her mother depends on me on a day to day basis. I accompany them to all doctor appointments, and weekly therapy sessions.

Without a home nurse, many of these innocent children would not receive proper care. Parents will have to quit their jobs to take care of their children or place them in a home. Private duty nurses allow these precious babies to enjoy living at home while providing an extra hand to their families so they can handle their day to day activities.

Please consider these babies and their families in your decision.

Thank you,

Robyn Stamps, RN

09/10/19

I would like to take this opportunity to express my concern over removing the modifiers for reimbursement for in home nursing care. If nurses trained to care for the medically fragile children are reimbursed at the same rate as nurses caring for a non-complicated child, I feel we will widen an already HUGE gap in services. Nurses will opt to serve the less involved children. This will be devastating to families dealing with providing complex care to their child on a daily basis. Their burden to care for their children has been lightened somewhat by skill nursing being reimbursed at a higher rate. I provide early intervention services in the home and have seen this need first hand. I ask that Medicaid PLEASE consider the ramifications of this average pay fee schedule.

Janet P. Slaughter, PT, DPT
Board Certified Clinical Specialist in Pediatric Physical Therapy
Associate Professor
Pediatric Residency Director
School of Health Related Professions/ Dept. of Physical Therapy
University of Mississippi Medical Center
601-984-6372

09/10/19

To whom it may concern:

This email is in reference to the proposed changes to the Private Duty Nursing Policy change #19-0023.

I am coming to you as a parent of a medically complex child.

For those of you that don't know, I'd like to tell you a little more about [redacted]. She is the light of our lives. She is a vibrant [redacted] who was born with [redacted] and, as a result, developed Infantile Spasm Seizures. Because of complications with feedings and seizures, she required a g-tube to get her the necessary nutrition properly and more easily, and further complications during her g-tube surgery necessitated a trach and a ventilator to help with her breathing. And just two weeks ago she had double hip surgery to correct her femur bones and then replace them back into the hip sockets. Although this will require [redacted] to be in a spica cast for 3 months it also brings hope that [redacted] could one day be mobile in her on way and at the minimum not have pain in her hips everyday. I tell you this not to elicit sympathy, but to give you a picture of her complex medical needs.

I understand the Private Duty Nursing Policy with our state Medicaid Program is undergoing many changes. To say it is important to our family is an understatement. This new changes directly impact the quality of care our child and family receives. To be completely forthcoming most of the changes being made are wonderful and it shows these children were considered while making them. It would allow [redacted] to live a much more normal life and provide the care she needs!

See as a parent of a special needs child my life isn't quite like others. It's just different. Not better nor worse just different. I not only get to be her mom but I am also an advocate, doctor, nurse, respiring therapist, physical therapist, occupational therapist, speech therapist, teacher and so so much more. And no one knows my child better than me, but there a few people that come close. Her nurses! Over time they have learned each and ever little grims and cry. They know what it looks like when she need help or assistance, they know when she is getting sick or having seizures. They know when to suction her so she can breath many times before she does. They know what her lungs sound like and if she needs CPT or treatments to keep them open. They know when she is getting sick or when she needs emergency meds and how to administer them to make sure she is ok. They know how to work her ventilator, oxygen machine, feeding pump, suctioning machine, Airway Clearance machine, and so much more. They know how to mover her and place her so that she doesn't hurt or get sores. They know how to encourage her to play and work to strengthen things like head control. To say they are extraordinary is an understatement. They are able to take some of those things off of us as parents and allow us to be just that her parents. We not only do we get to be her parents but be parents to two other amazing little girls who deserve our attention and time as much as she does.

We do however have major concerns about the reimbursement fee changes. The policy change 19-0023 seems to indicate the pay based on the level of care a child needs is being taken away. These pay changes could be catastrophic for our family! From my understanding, the new reimbursement schedule is based on an average pay for the entire state and does not take into account any specific training, experience or skills it takes to care of a child like [redacted]. It doesn't consider the area we live and how we must compete with others. It does not consider the nights, weekends, and holidays these amazing people work. It doesn't consider [redacted] equipment and diagnoses or the special training it take to care for her medical needs. It doesn't consider the skills and experience need to take lifesaving measures without the help of another nurse or doctor by their side.

For our daughter, and so many other children with medically complex needs, it is essential to have a RN who can provide quality, professional care. It is crucial these nurses also be confident and ready for any emergency situation that may arise. As you can imagine we do not just let anyone care for [redacted]. It has taken us 3 years to build a team of nurses that without a shadow of a doubt could and would do whatever it takes to keep [redacted] safe and at her personal best! This proposed change to modifiers or complexity for our child would change the level of care that can be provided. We have proven that quality of nursing care has as much benefit for [redacted] as it has for Medicaid, do to the fact that [redacted] has only been hospitalized once because of sickness since her trach. This is do to the diligence and critical care experience our nurses have. These nurses not only deserve to be paid for their skills, experience and training but for the abilities they possess to handle these types of situations.

It is disheartening to think that someone can say that all special needs/medically fragile kids require the same level of care and do not realize that certain kids like [redacted] are more complex.

All children are a gift from God and as such deserve every chance to reach their maximum potential while being afforded the same opportunities as typically developing children. To us, [redacted] is a joyful, loving, smiling sister, daughter, and friend, and I am sure parents, families, and friends feel the same about their special needs children.

It means so much to us that you would take the time to let us tell you about [redacted], and the special needs that she and many other children with severe medical complications face each day. Thank you for hearing our concerns and we urge you to reconsider these cuts and how it may affect the pediatric medically complex community.

Sincerely,
Rachel McCleave

09/10/19

I do not have a special needs child. I was one of the blessed ones with two healthy children. I do know several families who are not as fortunate. The loss of the nursing they need to make sure these precious children are taken care of is a tragedy. I really hope that this will be reconsidered before the changes take place. I am going to forward a copy of this to my legislators and Lt. Governor Reeves in hope that they will take steps to correct this problem.

Sandra Tabor
Counselor
Florence High School
232 Highway 469 N
Florence, MS 39073
601-845-2205
601-829-6943
stabor@rcsd.ms

09/10/19

It has come to my attention that Medicare is cutting pay for LPNs servicing in-home care patients. This totally makes absolutely NO sense! Their pay is already below minimum wage standards and frankly, I have no comprehension how that is even possible. While the remainder of the world seems to understand that Special Needs Children / Adults must have help to survive, why would Medicaid make such a decision?!

Please make the necessary changes to correct, not only this decision but to consider making their jobs more appealing by increasing their hourly wages. Please DO NOT force these wonderful people to seek work in a different field or setting. God called gifted people to these jobs. I know that personally. My grandson is one of those Special Needs patients who may not make it through the nights without the care of a nurse.

I will also be contacting our Senators, Tate Reeves, Jim Hood, our Governor and anyone else who might step in to rectify this decision.

Thank you for your time. My prayers are with you and those responsible.

God bless your day . . . PS 121
Cynthia Mabry :+)

Mississippi College

Telecommunications Operator
601-925-3000

09/11/19

Pleas don't make changes to private nursing. Kids such as [redacted] need special care that regular daycare can't provide, [redacted] has to be fed via a feeding tube and is at high risk to aspiration and pneumonia and can not fight colds and flu virus. kids like her need the private nursing . so please do not change it.

Kevin Edwards

09/11/19

I am sending this email on behalf of [redacted] and her daughter, [redacted].
I beg you to do whatever you can to stop this reduction. This specialized care is vital to this family and many others who are so unfortunate as to have a family member with special needs and must rely on help in order to provide for their loved ones and their entire family. Please help!

mrspig222@hotmail.com

09/11/19

Please don’t take home care nursing from our babies

Danielle

09/11/19

Dear Ms Wilson,

I am a Speech Pathologist at an early intervention center for children with special needs that provides services for a large variety and varying levels of disabilities in children ages birth to six. I understand that the legislature and Medicaid are looking to change the policies that govern private nursing services by eliminating the varying degrees and complexity of care that these children receive. Please take into consideration that one size definitely does not fit all.
Just as we as therapists and teachers are required to provide individualized care in our programming it is even more necessary that nurses be able to do this for these children. Children with more complex issues require much more training and expertise than do children with less complex conditions.

I ask that you continue to use diagnosis and rating that take this into consideration for the nurses that are able to provide these services. These nurses must make critical and often life altering decisions in a moments notice and must be qualified to do so. These nurses should also continue to be reimbursed based of the degree of skills needed.

Thank you for your help.

Sincerely,
Terri Kennedy MS-SLP

09/11/19

Please accept this email as an expression of my concern and objection to modifications which would affect reimbursement for private duty nursing for MS Medicaid recipients. If you need further information in support of this email, please let me know.

Amy Baskin

09/11/19

Hi Mrs.Margaret,

My name is Sydney Brady. I was informed today via Facebook about your possible salary change of the LPN nurses who do home care for Medicaid patients. I was informed that it was being lowered to as little as $5. I just wanted to reach out and plead with you to reconsider this salary decrease. If this decision is implemented, it could drop the number of hole care nursed dramatically. I used to babysit for a woman a few years ago who has two special needs children, one whom has a trach and requires 24/7 attention and care. This single mother is currently attending nursing school, taking care of her 3 children, and paying her bills all at once. She relies solely on her LPN nurse to take care of her son at night time so she can get proper rest.

She has told me many times when her nurse is unable to work, she has to stay up all night monitoring her son. She won?t get any sleep and will have to be a mother and go to school the next day. If her nurse potentially quits because of this decrease in pay, she will suffer severely because it. I?m writing to you on this woman?s behalf. Please reconsider your decision to decrease their salary and I even urge you to increase it. These nurses work hard and deserve compensation for their kindness and effort they show their patients.

God Bless you

From,
Sydney Brady

09/11/19

Ms. Margaret Wilson,

I am writing to request reconsider the division of Medicaid's recent state plan amendment 19-0023 on behalf of us and other families with disabled children. My wife and I have lived in Mississippi for 5 years now and both work at [redacted] in [redacted]. Our second son [redacted], now [redacted] was born with a congenital heart disease that required a surgery at birth and more surgeries in the future. He now has a feeding tube and must be fed every 8 hours. He has clinic appointments at least once a week. He is growing well, but he is very unstable. A cold or flu would be life threatening and certainly require hospitalization for medical care. Because of this [redacted] cannot attend daycare and must have someone with health-related training watch him. He qualifies for the disabled child living at home provision of Medicaid and we receive private duty nursing services from Hope Healthcare to assist with him. They allow him to be healthy and safe at home and not spend unnecessary time in the hospital. They provide an invaluable service by being available almost any hours that we need in flexible shifts that accommodate work, clinic visits, and emergencies. We do not have family in the state and caring for him has been an ongoing challenge that impacts us every single day. We have no fall-back other than Hope. They also allow us to continue to work and help other Mississippi families in our profession.

Amendment 19-0023 would represent a significant decrease in reimbursement for the private duty nursing services provided by companies like Hope. Families and children that rely on these services will be dramatically impacted.

Please do not let the state attempt to balance the budget on the backs of some of the most sick and vulnerable children in this state. As a parent, I hope you appreciate the importance of having someone that you can trust watching your children. I can tell you that this worry is only amplified by [redacted] illness. There must be a better way.

Thank You,
David Cretella

09/11/19

I am very upset about these rate changes. There are so many children and families who utilize this service on a HAVE to basis. This is only hurting the children that REQUIRE these services. If there is money needed for the program, how about cutting EBT down and making anyone who receives federally funded assistance be obligated to take a drug test every 6 months. I can guarantee that will free up A TON of funding that is being fraudulently acquired.

Sincerely,
Tara Dearman

09/11/19

Good evening,

Our pediatric private duty nursing provider recently informed us of some changes that might be happening with our Medicaid. These changes would negatively affect our son and entire family.

My son, [redacted],was born on December 7, 2017, and went thirty minutes without oxygen in the delivery room. We were told at first that he might not make it through the night- he made it. Then we were told he might be in a vegetative state if he did survive and be vent dependent- he started breathing on his own within two days of birth. He began meeting every milestone, and we were able to bring him home from the hospital on Christmas Eve.
On January 6, 2018 he was diagnosed with Congenital Nephrotic Syndrome. This is a fancy way of saying his kidneys don't work and he wouldn't survive without a ton of medication, infusions, dialysis, and future transplant. We prepared ourselves to live in the hospital until he was two years old and big enough for transplant. That was a very depressing time for our family because we also had a two year old daughter at home who was missing Mama and Daddy.

In March 2018 a friend of mine introduced us to Amanda Brasel, who is the owner of Hope Healthcare. She began to explain how we could have a life outside of this hospital where qualified nurses could take care of our baby boy. It was almost too good to be true!
We brought [redacted] home for good within a week of that initial meeting. [redacted] nurses gave him his twice daily 8 hour albumin infusions, they continue to give him his 30+ doses of medicine a day, they give him 8 ounces of a special formula through his g-tube every two hours so he can continue to grow, and watch him at our house so we can run errands and work. [redacted] has a compromised immune system and can't go to daycare. He will also have to have a kidney transplant in the near future, so both my husband and I have to work outside the home to save for future expenses.

As you can see we heavily depend on our amazing nurses who love our son like their own. We are begging you, do not pass this bill.

Trusting the Lord,
Jeff and Megan Jones

09/11/19

Hello Ms. Wilson.

My husband and I are members of a church with a single mom of three children: one with Autism and a 2nd that's had 20-something surgeries and still needs more, is fed by tube, can't speak or do hardly anything his 'normal' younger sister can. The father of these children has left all the work in her hands for the last time and divorce is underway if not final by now. She appealed to get a job that she can work from home and fortunately was able to do research and reports for my husband. She has to wait until a Respite nurse comes for the night watch to get things done - he's received emails at 1:30. Unfortunately it doesn't pay enough for 4 people to hardly exist. She once attempted to become an RN, but because of the hospitalization of the 2nd child, added to lack of funds or help with the children (mainly no Father present) - she had to drop out. With a year between, she's just signed up to try again for the one-year program (with pledges from our church members to help with costs). This is just one situation that relies on LPN home care....I'm sure there are thousands - all needing qualified nurse assistance, especially since the population of elders has increased immensely. If Medicaid cuts LPN pay, the professionals will have to go elsewhere so they can make a decent living. It will cause a snowball effect that will negatively affect so many households. I often wonder, Do the powers-that-be EVER consider the backlash of their decisions?

We met another young father of twins that are disabled...he's now a salesman - a graphic designer fresh out of college, then called into Ministry, but after their twins' complications at birth and the need to be hands-on more hours every week to relieve his wife...is now relying on a former employer's & church members' good-hearted attempts to help.

Disabilities require full-time parents, taking shifts... but someone has to pay the bills! They simply can't manage without the professional workers that Medicaid provides. This is the WRONG place to make cuts!

I sincerely hope you will do whatever you can to assure that LPN pay doesn't get cut and cause a flood of misery where very little normalcy now resides.

Thank you for your prayerful consideration of this matter. I pray you'll be the advocate for the needy that is required so our Medicaid system works as it should to help those who are truly in need.

Sincerely,
Stephanie Pruitt
Retiree

"He is before all things, and by Him all things hold together." _ Colossians 1:17

09/11/19

To Whom It May Concern:

My name is Christina Rushing. I am a single mother of three elementary-age children. Two of them have special needs, one of whom is medically fragile, dependent on both a tracheostomy and a jejunostomy tube. He is a lively, spirited, and loving little boy, but is unable to eat or breathe without medical intervention. He also has a seizure disorder along with numerous other medical issues. He requires 24/7 supervision by someone with appropriate training. We depend on PDN nursing in order to keep him alive and healthy, as well as, for our family to function. Without a nurse, I cannot sleep without significantly risking his health. I also rely on his nurses in order to afford me the ability to attend college, work, and take care of my other children, myself, and our house. My son's nurses are a vital key to keeping him out of the hospital and to keep the rest of our family from becoming dependent on government benefits (which in all likelihood would still prove inadequate). In my opinion, our nurses actually SAVE Medicaid and the state money.

Earlier today I became aware of new policies that would significantly reduce pay for our PDN nurses. It is already very hard to find reliable nurses for my son due to the complex nature of his case. I have been told by our nursing agency, there it is highly unlikely we will be able to find a nurse willing and able to work for the amount being suggested. This creates an unacceptable situation for my family and the families of so many other special needs children around our state.

I understand the financial hardships our state agencies face, but we can find better ways to make ends meet than by creating a potentially catastrophic hardship for our special needs families. We as Mississippians should be taking care of our own, especially our most vulnerable children. If we will not defend them, fight for them, protect them, and love them as the beautiful and precious people they are, who will? Please, as a mom and a citizen of our state, reconsider.

Sincerely,

Christina Rushing
217 Westfield Road
Ridgeland, MS 39157
601-826-7119

09/11/19

Dear Ms. Wilson,

I am writing you in regards to the Medicaid cuts coming our way, particularly cuts to private duty nursing and the changes in the hours required for PPEC. The Medicaid cuts will be catastrophic for children who need nursing care.

The Little Light House is a Christian early intervention center providing educational and therapeutic services, tuition-free to children birth to six years old. For over 14 years I have witnessed first-hand miracles and milestones many thought to be impossible. To date, 162 children have been given an opportunity to flourish through LLH's early intervention. Our community pulls together and supports our school through donations and fundraising efforts without accepting government assistance. We believe that given the opportunity, our students will thrive to fulfill the purpose God has created them for. Simply put…I'm asking you to believe in them, too.

It grieves my soul to think that our children with special needs are considered to be second-hand citizens or less by our society. Please stand up for those who are fighting to accomplish the very basics in life in the face of their disabilities. All children deserve the right to learn in their own way. If these cuts go through, the basic learning process that has worked so well at LLH will be shortened for many of our students, as they will be required to cut their day with us by 2 hours in order to meet the new PPEC mandates.

Please do not allow the Medicaid cuts to harm the future of our very Cap-ABLE students.

Tammy Tadlock
Event and Volunteer Coordinator
601.956.5131 (office)
601.624.5384 (cell)

Our Mission at The Little Light House is to glorify God by improving the quality of life for children with special needs, their families and the community.

09/11/19

To whom this may concern:

I am blessed to be a mom of a special needs child. My son [redacted] is non verbal, feeding tube, oxygen dependent, 24 hour care child. Before we recieved private duty nursing I was worn down everyday from the demands of being a full time caregiver. Their is nothing I wouldn't do for my son and he always comes first. With that being said i had to come to realization that taking care of myself was a very big part of taking care of him. I have to stay focused and in good health to be able to meet his needs. My son recieves 12 hours a day nursing in our home. He is a very sick child and we try to keep him home, happy, and well as we can. Having nursing in the home is very dear to my ❤. My son can be here at home with his family around him in a nice, quite atmosphere. [redacted] is [redacted] old but is still like a baby someone has to be with him at all times due to aspirating, and choking. Keeping [redacted] well is our number one priority taking him to hospitals or around others with his lowered immune system is very hard on him and can instantly put him in the hospital. Cutting private duty nursing is not the answer this will just cause more parents to depend on government aid, food stamps etc. Parents with Special needs kids want what every parents wants for their kids. We want to be able to provide for them and be able to work so we can buy wheel chair accessible vans and all the doctor visit trips out of state multiple times a month. Please look at this from all angles and the catastrophic affect it will have on these innocent sick children. They want to be at home with their loved ones. Please find it within your heart to shut this bill down.

Thank you
Lori Loden

09/11/19

Dear Ms. Wilson

I have read the 20 pages of letters that have been sent as of today.

The comments in these letters are valid and we all have huge concerns. My comments will not express the great need because you are seeing this over and over again in the letters and comments.

I am not sure who was on the committee when this decision was being made. Was there a mother, Nurse or Agency representative?

Could this decision be postponed at this time and additional solutions suggested.
My recommendation is to get a committee that includes all these parties to look at what sort of solution there is for these families. I understand that MS Medicaid may need to make some cuts.

As a lifelong MS resident and a RN that has worked in an agency since 1980 this is of the greatest importance. Additional research and more data submitted to assist Medicaid with making a much more feasible solution.

There has got to be other options and a compromise. I am more than willing to serve, provide data or whatever is needed to work through this sudden and significant planned change in the PDN reimbursement.
October 1 is not enough time for these families and nurses to get a safe and reasonable plan of how to move forward.

So many families and Nurses are looking to you and Ms. Medicaid for a solution. Lets work together to come up with a plan that is fair to all.

Respectfully Submitted,

Ann Barnes RN
President Prime Care Nursing
407 Briarwood Dr. Suite 201
Jackson, MS 39206
Office 601.977.8484
Fax 601.977.8128

Pcnursing.com

09/11/19

Dear Margaret, my name is Dustin. My daughter's name is [redacted]. She was born with [redacted]. She was diagnosed to not be able to be here with us at all. She was never supposed to make it out of the womb. My wife, [redacted] and has been wheelchair bound since birth pretty much. My daughter has a lengthy diagnosis list on paper. For instance, when we leave a doctors appointment dealing with her, the printout is 3 to 4 pages from meds to reminders of what she has going on. I can't work. Not because I don't want to. Because no one will hire someone even part time whenever they have to take their child to two to three appointments weekly including therapy. I have no health insurance. I have no income. Just my wife and my daughter. It's hard to place into words the activity involved with special needs children. I am sure you are getting them pages long and very well worded. I can't do that. I can't find the words that Express how living this way is. It's something a person must experience with the family just as these nurses do. I plead with these families, with these nurses, with these social workers, please do not take or be forced to take my extra set of hands away. Don't force these children to be innocent casualties of other abusers ignorance. There are parents willing to have their children at home with them. They know the hospital is no place to be. But in order to have their rest, sanity, and physical wellness we NEED OUR NURSES. OUR FAMILY MEMBERS. My wife and I went without nurses for so long because we could handle it. Now, she is [redacted] old. More complicated. More reliable on individuals like us for her daily needs. No matter the outcome, I can assure you of this...we love our daughter. We will continue to do what is in her best interest. That is not to have a secluded life in some hospital room cause she can't be home. Punish the ones that work the system not the ones that fight the system to work for them. Thank you for your time.

Dusty Carney

09/11/19

Good Morning,

My name is LaDonna Cooper, my son [redacted] was born with [redacted], where he was born with no hands, he also has a g tube. Our nurse has been with us almost 2 years now, she's an LPN. She is very good with Keshawn and he loves her so much. Yesterday I was informed on the reimbursement rate, please don't lower the reimbursement rate. Our nurse is really all I have right now. If you have any questions or concerns please feel free to contact me at 6019068636.

LaDonna Cooper

09/11/19

Dear Margaret Wilson,

I am the grandmother of a special needs child that currently receives care from a private duty nurse. The care that my granddaughter has received from her nurse and the nursing agency has been phenomenal and such a huge blessing to my granddaughter, her mother and our family as a whole. She has multiple complex medical diagnoses that warrant her need of this care such as: Cerebral Palsy, Gastrostomy tube dependence, Bilateral Hip Dysplasia, Dandy Walker malformation, Muscle spasticity, Neuromuscular Scoliosis, Spinal Fusion with rods, Developmental delay, Failure to thrive in childhood, Juvenile hemochromatosis, Glucosuria, Hypertriglyceridemia, HDL Deficiency and Incontinence. Without the care she receives from her private duty nurse, her health would suffer and possibly result in more frequent hospital stays. Please continue to support these types of services for those that are truly in need, and don't penalize the children for the greed of agencies that are exploiting a coding loophole for their own finanical gain. Thank you.

Sincerely,
Cindy Mixon

09/11/19

Today , I come to you with a humble plea for Private Nurses like my ex-daughter-in-law that takes care of me, her five children and her patients with a compassionate, loving and giving heart. Often times buying supplies needed at the less fortunate patient’s homes, to make their care to the level expected by these nurses.

My Brandy works an average of 100 hrs a week to support 5 children after my son abandoned them when he returned home from Afghanistan and exited the Army... I experienced first hand how hard these nurses work in July when one of her patients was sheltered at my home by DHS, to keep the high risk ventilated child from being moved states away to a facility, by child protective services. Please see if we can overturn this horrible decision!

Reducing the pay of these workers will not only hurt them, their families, but will cause an avalanche of homes lost, unemployment, food stamps and unemployable nurses.

Humbly and Respectfully ,

~Linda Rorie~

09/11/19

I received a very upsetting phone call this afternoon from [redacted] nursing service provider. Mississippi Medicaid has decided to lower the reimbursement rate for Private Duty Nursing services. The cut is so drastic that LPNs making $18hr would be dropped to $12hr. The service provider would not be financially able to staff services so unless this decision is overturned, we will lose our nursing care on October 1, 2019.

This is unacceptable! My child is medically fragile and needs this care. As a working single mother, I need her to have this care so I can provide for my family. My child is alive and well due to the amazing care she receives in my home by some outstanding nurses. She has surpassed all medical expectations due to the excellent care she receives.

I will be doing everything in my power to fight this decision, to continue to fight for the care my child deserves. If you would like to fight with me, please send an email to: Margaret.wilson@medicaid.ms.gov

Many thanks,

Tiffany Britt

Let me know what we need to do to fight this for these folks that work trying to have a life for there disabled children or spouses ! No LPN can work for 12 hr...

Thanks ,
Deborah Roye

09/11/19

This is a plea from a dear friend of mine who has a special needs child with a trach who also requires ventilator assistance to breathe at times. Her son needs a registered nurse with him to be able to assess when he needs assistance to breathe or her son can die. Please, please help her. She has already lost her oldest son to this disease.

Sincerely,

JC Cain

Dear Friends,

We need your help! So many of you have asked us over the years how can you help. This is it! We need you to write an email to Margaret.wilson@medicaid.ms.gov in order to help our sweet [redacted] keep the same nursing care he currently receives.

A hefty overhaul is in the works to the Private Duty Nursing Policy with our state Medicaid Program. The majority of this programs helps kids like [redacted] to get nursing at home. To say it is important to our family is an understatement. And to be completely honest most of the changes being made are wonderful. It allows [redacted] to live a much more normal life and provide the extra care he needs. It allows him to go to school, church, doctors appointments and any normal life activities with the help he needs. Previously Medicaid had a different reimbursement fee based of the level of care a child needed. For instance [redacted] received medically fragile and complex level of care and pay based on his needs. October 1, 2019 they are planning to do away with the modifiers that distinguish the difference in level of care a child receives. The results could be catastrophic for our family! The new reimbursement schedule is based on an average pay for the entire state and does not take into account any specific training, experience or skills it takes to care of a child like Raylan. It doesn't consider the area we live in. It does not consider the nights, weekends, and holidays these amazing people work.

For [redacted], and so many other children with special needs, it is essential to have a RN who can provide quality, professional care. It is crucial these nurses also be confident and ready for any emergency situation that may arise. As you can imagine I do not just let anyone care for [redacted]. This proposed removal of these modifiers(or complex codes) would change the level of care that a company can provided for my child. These nurses not only deserve to be paid for their skills, experience and training but for the abilities they possess to handle emergency situations.

It is disheartening to think that someone can say that all of our kids require the same level of care and do not realize that certain kids like [redacted] are more complex. All children are a gift from God and as such deserve every chance to reach their maximum potential while being afforded the same opportunities and assistance needed to do so. [redacted] is a joyful, loving, smiling brother, son, and friend, and I am sure parents, families, and friends feel the same about their special needs children.

So how can you help? Write an email. Let Medicaid, congressman and women, and our state representatives know this is not ok! It is imperative they don't see our children as a group but as individuals who require different levels of care and who deserve the best care. Let them know it is not ok to take away funding from our special needs children in this state!

We ask that you would join us in letting our politicians know this is not the way we treat our children or those who care for them! Please take a few minutes of your time to provide a voice for our children who can't! Please include Margaret.wilson@medicaid.ms.gov in your emails as this is the email we were provided to voice our concerns.

09/11/19

Ms. Wilson,

It has come to my attention that there are possible changes being made to the private nursing reimbursement program with the Medicaid program. I am urging you and those responsible that are considering these changes to not make these changes based on the many children that have no other options due to their illnesses.

Thank you,
Page Jordan

09/11/19