From:	<u>G&B Graham</u>
То:	HFS.BPPC
Subject:	[External]
Date:	Tuesday, January 14, 2025 6:16:57 PM

I believe this will be a great addition for parents who have raised their children and cared for them, which is never a day off from caring for them

From:	Edgardo Rangel
То:	HFS.BPPC
Subject:	[External]
Date:	Wednesday, January 29, 2025 12:07:45 AM

I think CNA parents would benefit a lot from being able to get paid for their own child as caregivers since they usually can't go out to work because their kids need special attention.

To Whom It May Concern:

I am writing In favor of the proposed Amendment of CNAs to become paid family caregivers. Services provided by CNA's that love and care for family members has lots of benefits. To begin I feel this will cut down on neglect of patients. This would also create mental security to family members that work outside of the home. By allowing this care to be provided by family members would ultimately cut down unemployment rates of employed caregivers and CNA's. Individuals that have to choose between caring for a loved ones or going to work would no longer be faced with said decisions. Employers would no longer have to terminate caregivers who are not CNA's due to excessive absenteeism.

There are other states who have implemented this program with much success. You would have patients who wouldn't have to go to assisted living facilities, skilled nursing facilities, and even hospice facilities. Also noting that you would have individuals who would live longer because they would not be kept at above facilities. In conclusion, I feel like 1915 (i) State Plan Amendment would be very beneficial to both Caregivers, Patients, CNA's and state health workers.

Thank You, Latoyia Wilson Hello,

Please see the attached comments (also pasted below) on the proposed 1915(i) amendment for family caregiver home health aide services.

Sincerely, Susan Agrawal MFTD Waiver Families, Founder

January 27, 2025

To Whom It May Concern:

Please find below comments on the 1915(i) state plan amendment that adds family caregiver home health aide services to the state plan. These comments represent the voices of more than 700 family members of children and young adults who participate in the MFTD Waiver.

Families strongly support allowing family caregivers to be paid to provide CNA or health aide services to their loved ones.

Families are concerned that no alternative pathway has been created to help them obtain a CNA license, especially since Illinois mandates in-person clinical hours. Many families are worried that they will not have enough nurses to care for their children while they are going through the process of obtaining their CNA license. Most family caregivers have already received extensive training through their hospital and home nursing agency. In addition, most current training programs focus on geriatric and nursing home care and are only somewhat applicable to the care that is required for children and young adults living at home. We urge HFS to work with IDPH and DSCC to create alternative training pathways for CNA licensure specific to family caregivers.

Thank you for continuing to improve the options available to children who require home nursing in Illinois, and we hope these comments are helpful in working toward even greater family-centered programs for children who are medically complex in Illinois.

Sincerely,

Susan Agrawal

Founder, MFTD Waiver Families

Dear Committee:

My daughter got pregnant in high school senior year and had a disabled child with no prognosis for survival.

I am a nurse, and My daughter, Miranda Walker, has taken care of my granddaughter who has made it to 20 years old. Miranda is better than any hospital CNA. My granddaughter has never had a bedsore while home, but got some while in the hospital.

Miranda does her tube feeding, urine catheters, repositioning, bathing. Assisted ventilator for 20 years and never got paid a dime.

Miranda has devoted her life and gave up employment because the state can't find CNA or RNs to care for my granddaughter.

Allowing certified CNAs to care for family is for the best care of the patient. Family CNA know the patients need. It would allow better care and decrease risk of hospitalization. If family work outside the home and leave the disabled patient, the patient is at a higher risk of harm, neglect and abuse.

I believe, with a degree in psychology BS. And BSN, RN it is in the best interest of the patient for family caregivers. It would also be cost effective and reduce hospitalizations and complications.

Thank you for considering this matter and I hope you decide in favor of paid family caregivers.

Sincerely Patricia Walker



From:	<u>Aja Emani `</u>
To:	HFS.BPPC
Subject:	[External] Approval - For Family Cna in home care pay
Date:	Wednesday, January 22, 2025 2:14:20 PM

Hey! I'm a 20 year old mother of a 1 year old tracheotomy and gastric tube baby, I'm emailing you guys today to put my input on the cna approval. As a mom who's been through a long and hard time of medical care, I finally now have my baby home for 7 months and it's the most best thing I could ever ask for!! I'm a stay at home mom, things happened in the past where I would rather stay and be with my baby to make sure he gets the highest quality of care! I've gotten trained to where I can do all his care by myself or with dad! I've tooken a cna class which was mentioned by my sons nursing agency, to tend to be able to provide and make a living for me and my son. I passed and became a certified NA! It would be great for the cna in home care to get approved for families for parents who stay home and take care of their medical children, and want to work a job and can't because of their baby and condition , or just no help at all and want to make a living for their family! Thanks so much have a good day!

Sincerely A Trach Mom..

From:	Abby Bauer
То:	HFS.BPPC
Subject:	[External] CNA amendment for families
Date:	Sunday, January 26, 2025 3:19:35 PM

Hello,

My name is Abigail Bauer, I wanted to share my input for the CNA amendment by giving a little bit of background of my story.

My son Mason was born a perfect healthy little boy. He was almost two years old when his accident happened in 2016. I was currently working at Rockford Memorial/ Mercy in Rockford as a CNA, I arrived to work for my scheduled shift and was just about halfway through my shift when I received notice that my son was in the emergency room. I ran to the ER and was brought back to a trauma room where my son was currently receiving life saving measures. In that same room I saw my son's father dripping wet and knew that my son had drowned. That day plays constantly in my head. I took some time off of work because I had to learn how to change my entire life and learn how to take care of my now very fragile medically dependent child. My son spent about a month and half in the hospital and was then shipped off to Chicago for rehab, where I learned how to care for his tracheostomy, His feeding tube, give medications, and administer feedings. I also had to learn how to best administer therapies. My medical background helped me significantly in these areas, but it was different and very taxing to have to relearn how to live my everyday life. When my son came home we had no nursing, there just simply wasn't any nursing available for us. My son's father would watch him during the day and I would check on them everyday on my lunch break at work, because I had to go back to work fulltime. There was simply no other option. We did eventually get nursing but that didn't last as nurses frequently move on, I had to again take time off of work as now I was a single mother with no help from my son's father and no nursing staff. I eventually had to quit my job, with the loss of our picu at mercy and having to now travel to get my son care when he was ill, and having no nursing at home I couldn't work any longer. Not being able to provide for myself and my son has been a struggle, I have all of the tools I need to be able to care for my son at home. He is now 10 years old and needs more care now than he did when I initially brought him home in 2017. I am hoping and praying that This amendment fully goes through and is approved. It would be beneficial for so many families who can't work because we are caring for our children 24/7 with minimal to no other help. Being able to be paid for the work and care we already proved for our children will be a huge blessing.

Thank you for your time and consideration.

Sincerely Abigail Bauer (Mother of a technology dependent child)

From:	<u>shahzad akram</u>
То:	HFS.BPPC
Subject:	[External] Cna as paid family caregiver
Date:	Friday, January 3, 2025 10:00:16 AM

Sent from my iPhone

It is a step in the right direction being a parent of medically fragile child I know how it is trying to balance work and home life this will allow to reduce stress and will cause an positive effect on their daily lives

From:	jon.dudley
To:	HFS.BPPC
Subject:	[External] CNA as Paid Family Caregiver
Date:	Thursday, January 2, 2025 6:48:51 PM

It is critical that parents & caregivers who are CNAs become paid caregivers to help support their family that need in-home nursing. The proposed amendment 1915(i) SPA must be approved to help these families.

My daughter had to resign from a career that helped support her family for everyday needs because it was crucial my granddaughter had 24/7 care that nobody else could cover. Outside Nurses and CNA's are just not available through agencies and even when they are the hours are not 24/7.

If it requires an amendment to the Medicaid Home & Community-Based Services Waiver for those Medically Fragile, Technology Dependent (MFTD) and the creation of a new state plan amendment then that is what needs to be done promptly.

Your promptness and time spent on this proposal is greatly appreciated.

Jon Dudley Grandfather to MFTD child

Sent from Yahoo Mail for iPhone

Hi,

I believe allowing CNa's to cover for medically fragile kids should be allowed. In my situation, there is a shortage in nurse coverage for my daughter.

I am in my career, but I have been considering obtaining my CNA Liscense to help my daughter out and to be able to care for her while still getting paid. This program would better align with my current schedule vs a LPN or BSN program given that I already work 9-5 and my free time is very limited.

Ashley Grooms

From:	<u>Jan</u>
To:	HFS.BPPC
Cc:	Jan Dudley
Subject:	[External] CNA Paid Parent Caregiver
Date:	Thursday, January 2, 2025 6:33:15 PM

Sent from my iPhone

It is critical that parents & caregivers who are CNAs become paid caregivers to help support their family that need in-home nursing. The proposed amendment 1915(i) SPA must be approved to help these families.

My daughter had to resign from a career that helped support her family for everyday needs because it was crucial my granddaughter had 24/7care that nobody else could cover. Outside Nurses and CNA's are just not available through agencies and even when they are the hours are not 24/7.

If it requires an amendment to the Medicaid Home & Community-Based Services Waiver for those Medically Fragile, Technology Dependent (MFTD) and the creation of a new state plan amendment then that is what needs to be done promptly.

Your promptness and time spent on this proposal is greatly appreciated.

Jan Dudley Grandmother to MFTD child Hi,

I know many families who would benefit from this law being passed. Often times they have to continue to work to pay medical bills and it's very hard to do so when you have a child with medical complications at home.

Thank you,

Kara

From:	Mic Mac
То:	HFS.BPPC
Subject:	[External] CNAs as Paid Family Caregivers
Date:	Monday, January 6, 2025 3:49:23 AM

As a parent of 2 waiver children I think this is long overdue. Thank you for allowing parents to be paid caregivers to their children. It will help so many families to pay their bills while they insure the best care for their children. Too many parents are forced to seek institutional care for their child due to the financial hardship caused by low staffing of their case, causing parents to lose their jobs. BRAVO!!

Mchele Mcullough

From:	Katrina Harden
То:	HFS.BPPC
Subject:	[External] CNAs Pay For Family Care
Date:	Saturday, January 4, 2025 3:26:34 PM

Thank you for the opportunity to discuss why I feel CNAs should be paid to take care of family members.

Firstly, these patients need specialized care and these services are very expensive and mostly uncovered by insurance.

Secondly, who is better equipped to take care of these patients than the ones who love them and are willing to participate in their care.

Thirdly, although these providers are taking care of family members, they should absolutely be paid. Just because you are caring for a family member does not negate the need to survive. Please take this under consideration. Thanks!

Trina Harden

I am writing to express my strong support for the proposed amendment to the Medicaid Home and Community-Based Services Waiver for Those Who Are Medically Fragile, Technology Dependent (MFTD waiver), as well as the creation of a new state plan amendment. These changes are crucial for allowing parents and caregivers who are certified nursing assistants (CNAs) to become paid caregivers for their children.

Currently, parents and legal responsible adults (LRAs) are compensated for providing skilled nursing services to their children if they hold an active registered nurse (RN) or licensed practical nurse (LPN) license. This rule applies to parents/LRAs of all children approved for Home Care Program services, regardless of the child's age. However, this leaves out many capable and dedicated CNAs who are also providing essential care to their medically fragile, technology-dependent children.

Allowing CNAs to be paid caregivers is an important step in strengthening support for families like mine. As a CNA, I possess the skills and training necessary to provide high-quality care to my child in a home setting. This change would not only recognize the valuable contributions of CNAs but also ensure that our children receive consistent and familiar care from those who know them best.

The approval of these amendments is vital for families who rely on in-home shift nursing. It would provide financial stability and peace of mind, knowing that we can continue to care for our children without the added stress of financial strain. I urge you to consider the positive impact this change would have on countless families and to support the necessary amendments to the MFTD waiver and state plan.

Thank you for your attention to this matter and for your continued support of families with medically fragile children.

Sincerely, Kimberly Ingoldsby Sent from my iPhone

From:	Janette Jones
To:	HFS.BPPC
Subject:	[External] Feedback for MFTD waiver amendment
Date:	Saturday, January 11, 2025 8:43:41 AM

My name is Janette Jones. We have 3 daughters, our youngest is on the waiver program. She is almost 7 years old and was born with lots of rare medical complexities. She has a trach and feeding tube and has been ventilator dependent since birth. She also has heart conditions among other things. She undergone over 20 medical procedures in the past 7 years.

Our family went down to 1 income out of necessity when she was born. She requires 24-7 nursing care and the majority of that has fallen on us despite constant nursing recruitment. I do have a professional degree, just not in nursing. However, I have been highly trained in all her care by the Cincinnati Children's Hospital, they consider me her medical professional. I train all the RNs that have worked in our home, yet I've never been compensated for shifts I've covered in the past 6 years. I could currently turn in over a hundred hours A WEEK that I am medically responsible for her.

I've been listening to talks of this amendment for years. About a year ago it really seemed like there might be hope. As hard as it was, I completed a CNA course to get paper required. My mom came to live with us to help in my absence when I was in clinicals full-time. She also was trained in Cincinnati in my daughter's care. Having a medically fragile child is life-changing. But having this waver go through would restore our family in so many ways.

When I was told that it would not initiate January 1st, I was heartbroken. Now, am additional \$2000 in debt from schooling costs, the bills keep piling up as the economy gets tougher by the month. The strain on our family seems never ending.

I encourage and plead to you to move this along as fast as possible. Don't wait for deadlines.

Sincerely,

Janette Jones

Sent from my Verizon, Samsung Galaxy smartphone Get <u>Outlook for Android</u>

From:	Cameron Cornell
То:	HFS.BPPC
Subject:	[External] Feedback on the plan to allow parents with CNA license to be paid as a caregiver of their sick child
Date:	Thursday, January 9, 2025 9:27:48 AM

The proposed plan to allow parents with a CNA license to take care of their disabled child is nothing other than a wonderful plan and necessity. I myself am a parent of a disabled child who qualifies for nursing care. There's nothing I want more than to be able to take care of my child, but the current system forces families like mine to rely on strangers and outsiders. Yet I am the one most qualified to take care of my child because I have been there from the beginning. In addition, if I can get my CNA license and stay home with my child, this will alleviate the burden on the nursing shortage and the available funds for families who are unable to take care of their children.

The longer you delay in making this plan into law, the more stress and anxiety you put on families like mine. Illinois has the opportunity to become one of the best states in the country for families with disabled children. We can lead the way in the country as a state known for compassion and wisdom.

Thank you.

Yours, A tired disability Dad and Mom.

From:	Miranda Walker
То:	HFS.BPPC
Subject:	[External] Feedback regarding allowing CNAs as paid caregivers
Date:	Thursday, January 9, 2025 1:40:12 PM

My name is Miranda Walker. I currently have a very medically complex child that is nonverbal in the DSCC program and receiving nursing services. Finding a nurse to work with your child and family is not easy. The pay for a nurse working in a home agency is much less than one working in a hospital or clinic so there is not a lot of incentive for nurses to become home health nurses.

It can be very difficult for families to find nursing care at home for their child. Parents need to be able to trust that this person is doing their job correctly, especially when that child has trouble communicating, and there are a number of other family dynamics at home that can make it difficult to find a good fit.

There is also no guarantee that a nurse will stay working with your child if they end up having to stay in the hospital for an extended period of time, which leaves you looking for another nurse for months at a time sometimes. All of these circumstances make it extremely difficult to find a job for yourself.

My family is very large, we have two adults, and a combination of 6 children, so 8 people in my household. Living on one income is extremely difficult for so many people. I have found a nurse that seems to be working out for the daytime. It is still difficult to find nursing at night due to my pets at home, weekends are extremely hard to find help with, and if your nurse can't make it in, there isn't anyone to call in that can learn how to take care of your child that fast so now you would need to call off.

I really hope that an amendment can be made to allow parents/legally responsible adults of persons in the program. It is nearly impossible for a person to find a job of any sorts, or keep one if you can manage to find one. Parents with an LPN or RN can become paid givers for their child, it is much for parents to be able to be CNAs as well, it is much needed for my family, and I've spoken with many others families that claim the same. Sincerely,

Miranda Walker

Yahoo Mail: Search, Organize, Conquer

I believe parents should be allowed to be paid caregivers for their children with disabilities as long as they are certified and hired through an agency. Colorado already has this in place and I know families moving there for that very reason. Many parents want to care for their children, and most can provide them with the best care possible, so instead of leaving their children in the hands of others (who may or may not be reliable) to go work their own hours, it makes the most sense to allow parents to do this. I also believe it would be in the best interest of most of the children.

I also believe the waiver needs to expand beyond medically fragile children. My daughter has many chronic medical conditions and disabilities resulting from a stroke including epilepsy, hydrocephalus with a VP shunt, moderate intellectual disability, and developmental delays. I feel children with high degree of disability where constant supervision is needed, parents should be allowed to be paid caregivers.

I had to leave the workforce 14 years ago after receiving my doctorate degree to care for my child post-stoke. I have still only been able to work online part-time recently due to her constant needs, appointments, and homeschooling her (as a traditional environment for learning has not worked for her).

My husband is active duty Army and we were recently relocated to Illinois from Colorado and we qualify for MUCH fewer services in the state of Illinois. (no services except "care coordination" through UIC which isn't something we benefit from and are sitting on a PUNS list with a 5 year wait period). No parents at my age should have to have fewer than \$35,000 in savings for our future to qualify for services!! Illinois needs to support all families with children with disabilities regardless of parental income.

Lindsey M. Larsen, OTD, OTR/L, ASDCS

From:	Michelle Yeley
То:	HFS.BPPC
Subject:	[External] LRA as CNA
Date:	Friday, January 3, 2025 10:19:29 AM

This is a brilliant plan. As a parent of a medically complex child, I am so thankful for our nurses. However, with so many hospital stays it's been difficult to keep a job with having to take so much time off for appointments and hospital stays. This would help our family so much financially. It would also still allow me to have a nurse part time, so that I get to be "mom" still. Sometimes, I get caught up in all the medical jargon and responsibilities that I forget I am my child's mom too. If there was an option for parents who aren't CNAs to become one through the state that would be fantastic. Maybe something accelerated. I feel so many of us have become experts and could handle a fast pace to become certified.

Sent from my iPhone

From:	Bill Van Tuinen
То:	HFS.BPPC
Subject:	[External] Paid care for familie members of medically-complex and fragile children
Date:	Sunday, January 5, 2025 8:23:31 AM

Hello - I am advocating for family members to be paid caretakers for medically complex and fragile children. When our now 3-year-old was born in late 2021 my wife was an active freelancer, billing nearly 6 figures annually for several clients. Knowing our daughter would need a lot of care, she shut down her business ahead of her due date, but due to an early arrival, she was literally finalizing work for her last client while in labor at 3am. She has spent the last 3 years doing unpaid work for our daughter, Hazel. Navigating the bureaucracies of medical care, insurance coverage, and therapy/schooling in addition to caring for our other 3 children has put a physical, emotional, and financial strain on our family. Additionally, we are utilizing, higher-cost RNs for our child's care whenever we can. If our family could be trained as CNAs, it would likely result in similar overall compensation, higher quality care for our child, and it would also release more nurses to help those who aren't able to provide care to their child. Relieving the shortage of nurses would be an additional benefit of this policy.

Best Regards, William Van Tuinen

From:	Anitha Riggs
То:	HFS.BPPC
Subject:	[External] Paid caregiver
Date:	Sunday, January 12, 2025 7:47:40 AM

This program would be beneficial. I am the grandmother who takes care of my grandson who is Paralysis from the shoulders down. We do have some nurses in the home but we have alot of unfilled shifts. I am a CNA and being able to get paid to assist my grandson would be a life changer, having to schedule my work hours around the nurse can be challenging. And my job is not always understanding to the fact that I must make sure he has coverage. Passing this law would benefit many families who are the primary caregiver. Thanks

<u>ie Duzan</u>
S.BPPC
ternal] Paid caregivers
irsday, January 30, 2025 4:27:18 PM

I am in agreement with allowing paid caregiver status for families of disabled children Sent from my iPhone

From:	Angela McKenna
To:	HFS.BPPC
Subject:	[External] Paid Family Caregivers - Public Comment
Date:	Sunday, January 5, 2025 11:10:54 AM

To: Illinois Department of Healthcare and Family Services

I would like to submit a comment on the proposed amendment to the Medicaid Home and Community-Based Services Waiver for Those Who Are Medically Fragile. It is extremely important for parents/legally responsible adults (LRAs) to become paid caregivers for their children at home. Most of our children are unable to attend daycare centers or community programs. I cannot hire a local babysitter or nanny. My extended family members are too nervous to care for my child. My husband and I are reliant on support from nurses, and that support is difficult to come by.

My son is now 18 years old. We are desperately trying to provide for our family, give high-quality and constant care to our child with extreme medical and physical needs, and take care of our own mental health. We need help. Since the staff is not available, being able to be a paid caregiver would relieve some of the burden.

My input involves requiring parents in our position to become CNAs. We do not have the time or the financial resources to take the classes. From what I have heard, the classes may not even be relevant to the day-to-day care of our child. We are experts who have done the job for 18 years; asking us to take the class is insulting. I would be willing to participate in a free online seminar or attend a clinical/hands-on class on a weekend, but having us complete a whole CNA program is not appropriate. There needs to be a modified option for parents in our position.

Thank you for your consideration, - Angela McKenna

JeannaRobert Polacek
HFS.BPPC
[External] Paid Parent CNA comment
Thursday, January 2, 2025 4:14:34 PM

Hello, I wanted to thank you for putting this through. My daughter, Mia, age 5 is very dependent and I had to quit my job a few years ago. It was difficult for me to complete a 5 week CNA program, but we managed. I cannot complete a 2 year nursing program with my daughter's needs, minimal home nursing available and having another daughter in addition to Mia. A CNA is manageable for most because it's a short period and it allows ALL parents of these children who have had to quit jobs and cannot get another one to be paid not just those that happened to be nurses before their child was born disabled. This will help our family so much. Nursing is so hard to find stability and help and even if you find a good nurse it's almost impossible to hold a job because the second my daughter is hospitalized or anything, they quit.

Thank you for helping families like mine.

Jeanna Polacek

mom to Mia MFTD waiver Sent from my iPhone Hi,

I wholeheartedly support that parents should be paid as CNA Caregivers for their children. Parents do more work then the doctors themselves do and should be compensated as well.

Thanks,

Pamela Rovello

From:	Sandy Hernandez
То:	HFS.BPPC
Subject:	[External] Proposed CNA family caregivers
Date:	Thursday, January 2, 2025 4:50:55 PM

Yes please approve this as there is such a shortage for providers and this would help provide care for those in need.

Sandy Hernandez Sent from my iPhone

From:	<u>Ty Dugar</u>
То:	HFS.BPPC
Subject:	[External] Proposed CNA plan
Date:	Thursday, January 23, 2025 11:16:06 AM

I agree with this caregiver plan for parents or caregivers to be paid to care for their own minor children. I have a specials needs child who has a nurse who can only come twice a week leaving my daughter without care after school. We can't get a cna because of her intense medical needs which I am trained and licensed to care for and allowing me to be paid to care for her will allow me to still provide for my family without relying so heavy on government assistance but still care for my child's needs.

Please approve this plan

From:	Chelsea Hadley
То:	<u>HFS.BPPC</u>
Subject:	[External] Public Comment Notice - Family Caregiver Home Health Aide Services Amendment
Date:	Tuesday, January 14, 2025 9:21:28 AM

Hello,

Reaching out regarding HFS' request for public input on state plan amendment for family caregiver home health aid services. If approved, this could make all the difference for so many families. Many parents cannot hold a job due to their child's medical needs and/or inability to maintain regular nursing. Getting a CNA license is feasible for a lot of these families and, in my opinion, they deserve some sort of compensation for taking care of their medically fragile children especially if they cannot work. PLEASE take this into consideration and think of how many families you could help not just financially, but mentally and emotionally too.

Thank you for your time, Chelsea

Sent from my iPhone

Dear HFS,

This letter expresses my strong support for the proposed 1915(i) State Plan Amendment to allow more parents/legally responsible adults to become paid caregivers for their children on the MFTD waiver.

The inclusion of paid family CNAs will provide invaluable support to families of children with complex medical needs. Many families have been forced to make the difficult decision to leave their outside employment to provide 24/7 care for their children, resulting in significant financial hardship. This amendment offers a lifeline by providing:

- **Financial Assistance:** Compensating caregivers for the vital work they perform will alleviate financial strain and improve the economic stability of families.
- Enhanced Child Care and Quality of Life: Allowing parents/LRAs to care for their children without worrying about obtaining outside income will ensure children receive consistent and high-quality care, potentially improving their health outcomes and overall quality of life.
- **Increased Sense of Purpose and Validation:** This program will recognize and validate the invaluable contributions of family caregivers, providing them with a sense of purpose and a renewed sense of self-worth.

I understand the significant challenges the administration faces in navigating existing state laws to ensure both the protection of children and the support of families. I acknowledge the importance of carefully considered guidelines and requirements that balance the needs of families with the paramount importance of child welfare. It is crucial to recognize that arbitrarily limiting the number of hours a parent can work as a CNA for their own child will not improve outcomes for the child. As parents, we will continue to provide necessary care for our children regardless of any imposed hourly limitations. This amendment simply allows us to be compensated for the essential care we already provide. Limiting our hours will only increase caregiver stress and financial instability, potentially leading to negative consequences for both the caregiver and the child.

While some restrictions are necessary, I urge the administration to consider the following:

- **Compliance with the Illinois Nurse Practice Act:** Ensuring all care provided meets the highest professional standards. This includes but is not limited to working a maximum of 16 hours within a 24-hour period with an 8-hour break between shifts. It also requires overtime to be paid above 40 hours a week, preferably at a rate of time-and-a-half.
- Adherence to federal and state labor laws: Protecting the rights and well-being of both caregivers and their children. This includes but is not limited to, provisions related to minimum wage, overtime pay, breaks, and workplace safety.
- Staying within the approved care budget: Ensuring responsible and sustainable utilization of allocated resources as determined by the Division of Specialized Care for Children (DSCC).

By adhering to these guidelines, the administration can ensure the safety and well-being of children while providing much-needed support and recognition to dedicated family caregivers.

I urge the administration to prioritize the swift and effective implementation of this crucial amendment. I believe that by carefully considering the needs of families and ensuring the highest standards of child safety, this program can make a profound and positive impact on the lives of children with complex medical needs and their families in Illinois.

Sincerely,

Melanie Turenne, parent of MFTD waiver participant Theodore Boffo

--Melanie Turenne

From:	Michael Graham-Cornell
То:	HFS.BPPC
Subject:	[External] Support of 1915(i) State plan Home and Community-Based Services Administration and Operation
Date:	Sunday, January 26, 2025 2:00:24 PM

We are writing to provide our support for the Illinois 1915(i) State plan Home and Community-Based Services Administration and Operation modification that would allow parents of qualified children to be paid as a CNA. Our grandson requires care under this plan, and we believe that our son who will soon receive his CNA is the best person to provide this type of care for our grandson. In general, we believe that parents of these incredible children should have the opportunity to be paid to provide this care - there are just not enough professionals interested in this type of service to cover all of the needs of all of the kids. But the parents are passionate, knowledgeable, and caring adults who want the best for their child.

While we no longer reside in Illinois, we both grew up there, and we are proud that the state cares so much for these children. So many states do not have the level of support that you provide. This is another way for Illinois to show the rest of the country how this should be done properly.

Gratefully,

Michael and Shannon Graham-Cornell





MFTD Waiver Families

www.mftdwaiver.org mftdwaiver@gmail.com

January 27, 2025

To Whom It May Concern:

Please find below comments on the 1915(i) state plan amendment that adds family caregiver home health aide services to the state plan. These comments represent the voices of more than 700 family members of children and young adults who participate in the MFTD Waiver.

Families strongly support allowing family caregivers to be paid to provide CNA or health aide services to their loved ones.

Families are concerned that no alternative pathway has been created to help them obtain a CNA license, especially since Illinois mandates in-person clinical hours. Many families are worried that they will not have enough nurses to care for their children while they are going through the process of obtaining their CNA license. Most family caregivers have already received extensive training through their hospital and home nursing agency. In addition, most current training programs focus on geriatric and nursing home care and are only somewhat applicable to the care that is required for children and young adults living at home. We urge HFS to work with IDPH and DSCC to create alternative training pathways for CNA licensure specific to family caregivers.

Thank you for continuing to improve the options available to children who require home nursing in Illinois, and we hope these comments are helpful in working toward even greater family-centered programs for children who are medically complex in Illinois.

Sincerely,

Susan Agrawal Founder, MFTD Waiver Families