



**Connecticut Medical Home Initiative for
Children and Youth with Special Health Care Needs***
Connecticut Lifespan Respite Coalition
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My name is Joy Liebeskind, and besides being the parent of 2 young adults with special needs, I am the Coordinator of The Ct Lifespan Respite Coalition. We have a contract with DPH which is part of Title V, The Medical Home Initiative. We handle the Respite and Extended Service pieces of the program statewide.

We just learned in the last few days that our program was part of a line item cut to the budget. The Medical home line got a 10% cut. It doesn't seem like a lot of money, but 94,000.00 is set to come out of Respite Funds. That will mean that 188 less families will get respite for their children This year and again next year. 188 families that care for children with many medical needs that make them require more medical care than their typical peers. And remember that they have siblings missing out on lots of events, and parents trying to fit all this care in and maintain a normal family life, and often work to keep these kids insured. This cut will also result in the wait time going for 10-12 months, to about 3 years in the next year or so.

Currently families get a respite check of 500.00 and then need to wait One year till they can go back on the wait list. Then families wait 10-12 months till they get to the top of the list to get another check. This is a very small program, but for many of our families it is the only help they qualify for. Respite is the most often mentioned service family caregivers request. Respite helps keep families together and able to care for family members at home.

Even the small amount of respite our families receive now is not enough for many, but we continue to work with them on increasing time with mothers helpers, volunteers, forming groups or co-ops so they can go on doing their important job of caregiving. Many of these caregivers live on the brink financially, and with acute medical situations. There is a shortage of trained caregivers they can hire even when they have services approved, so many go 24 hours or more with no sleep often while they care for their children. This put the whole family under stress.

I know this state has lots of problems financially, but this cut will hurt each of those 188 families this year. Most have no where else to go. This program gives them moral

support, knowledge, and a small amount of funds to go on. I hope that you can see a way to restore this small pocket of money so needed by some small citizens of our state. I have included comments from some families that come back on their expense forms after they get funds. This is only a few. I could pull you hundreds.....

Thank-you for your time and please feel free to contact my office with any questions you may have.

860-513-0172 or cell 203-641-0679

Thank-you so much for the respite check. You will never know how much it meant to me. My mother is going through Chemo treatments and I felt like I really needed to be there for her, but couldn't afford to travel. Then the check arrived. Tommy and I used it to drive home and spend 2 weeks with my folks. Tommy and my dad went fishing, hiking and lots of outside activities. I took my Mom to her treatments. You will never know how much this meant to all of us.

A Mom from East Haddam

I wanted to let you know how we spent our respite check. We love to get away for weekends, but my son screams when cooped up in a hotel room. We purchased camping equipment at COSTCO and went away for our first weekend. It was great to get away from home. Our other 2 kids had a good trip also. . No screaming! Now we can get away often. The break is great! It is really nice to do something as a family.

A Waterbury Family

I was so surprised when you told me I could hire someone to care for my daughter while my husband and I went out to dinner with our check. We have not ever left her, and haven't gone out to dinner alone since she was born seven years ago. It was heaven. We saved the rest to do it once a month for a few months. Just knowing we can get away has helped with the stress of her surgery planned for next month. I can't say thank-you enough times. We hope we will be able to get this help again in the future.

A Fairfield Family

We have 3 children all with different problems. We do not have any family in CT. We moved here for my husband's job, but it was very hard to leave our family and Ct is a very expensive place to live and I can't work since there is no one to watch the kids. Respite and the help of your money has made a very big difference for us. I took your advice and got volunteers to take the two boys out in the community. They are both doing scouts and swimming with their teen friends. I get to spend time with my daughter while they are out. We took our check and joined a YMCA so we all get to swim as a family as well as the kids taking swimming lessons. Thank-you to everyone in your program

3 happy kids in Groton

Thank-you for taking the time to speak with me the other day & sending me the application form. As a single mother of a 17-year-old daughter with a diagnosis of bipolar there are some days that are very hard to get through and I have no family to help. Thanks to your advice I did get a college student who will come and spend 4 hours twice a week with her either at my home or on campus. I am still looking for a home that would take her for a weekend now and again, but this has been a big help. You don't know how hard it is to be on duty 24-7. I work very limited hours since often her school time is the only sleep time I get. I look forward to getting a respite check from TitleV in the future. Thank-you so much.

Mom from Wilton

I was so excited to meet you at the conference recently. I do have a copy of the respite book, but had not filled it out till after we spoke. We used it this past weekend we left our 2 boys with Autism at home with an aide, and used our respite check to go away to a family wedding. The boys are 4 and 11 and it was the first time we have ever left them with someone else. It was so good to both get to go to a family event together. What a wonderful break. We look forward to getting back on the respite list and doing this again some time.

A Southington Family

What a great idea you gave me. When I called your office for help I really didn't think I could afford Respite care for my mother. Now I have signed up for a program with the Area Agency on Aging just as you suggested. It worked so well I decided to try a volunteer like you suggested to help keep Mom busy and free some of my time. A young nursing student from a local program has been lined up to come sit and read to Mom two afternoons a week. I feel like a new person. I am not alone and I can now go visit my grandchildren and see their sports activities with out worrying about Mom. I wish I had found this help earlier. I will spread the word to other friends that are caring for their elderly parents that help is available.

Family caregiver in Torrington.

Wanted to let you know we got your respite check in the mail last week and we immediately signed both kids up for 2 weeks of summer camp. They are so excited to get a chance to go to camp like other kids from school. With all our medical bills they have never been able to go before.

2 happy kids from Clintonville

Thank-you Thank-you

MY FAMILY WAS IN DESPERATE NEED WHEN OUR RESPITE CHECK ARRIVED. WE BOTH REALLY NEEDED TO GET AWAY FROM IT ALL, AND OUR PARENTS WERE ALSO HAVING MEDICAL ISSUES THEY NEEDED HELP WITH. I GOT TO SPEND SOME TIME WITH MY OTHER SON WHILE A SITTER WATCHED MY BOY. WE ALSO GOT A SITTER TO STAY WITH THE BOYS FOR A FEW DAYS WHILE WE WENT TO VISIT AND HELP OUR PARENTS. IT WAS TIME I REALLY NEEDED TO RECDUP TO BE ABLE TO CARE FOR MY SON.

A WATERBURY FAMILY

Respite is very important to our family. My husband travels a lot for business which means I am the only parent home with 3 children. My son has CP and uses a wheelchair all the time. He is also nonverbal, so it is hard to find someone willing to care for him. After school programs won't take him so I do all his care. I also care for my mother who lies in the next town, but barely can lie alone any more. She used to be my back up. We really appreciate that week off we get when he goes to the respite center. My other kids also really like the special attention they get during that week also.

A Mom from Cromwell

We use our respite check for camp whenever we get one. My daughter loves her week at camp but without your help we would not be able to send her as my wife stays home to care for her and with all our medical bills it is very hard to provide extras on one check. Thank-you for your help.

A Dad from Stratford

The respite check came just at the right day. We were going to visit grandma, my daughter's favorite person. The air conditioner in the car died. We were staying home since my daughter can't travel without it. I had no idea how I would tell her the trip was off. I said a prayer to give me the words I needed, and half an hour later the mail came and there was our respite check. The next day we again left on our trip with AC working. It was the best break we could have gotten.

A grateful Mom in Barkhamstead

You ask why respite is important to our family. Siblings need time also. My twins need not to feel like it is their fault we never get out. My husband works hard to support us and help with the twins when he is home. He deserves a night out once in awhile. We try to stretch our respite checks over 5 or 6 months. A movie night with siblings one month, dinner out one month, you get it. It is what keeps us going. I wish there were more funds available to families like this.

Thanks from Madison Ct

We received our respite check in the mail today. The suggestion list was a big help. We went over night to Co-CO Key Resort and my son thought it was the best thing he had ever done. The Hotel had a list of local sitters available and for the first time ever since we had kids, my husband and I went to dinner alone. (Knowing we were in the same building). It was heaven! We have made reservations to have a fall weekend in Mystic. These great memories will keep us going over many of the rough days. We can't thank you enough.

A New Milford Family

My children go to camp for the first time this year. Thank-you. God Bless. We never think we get help like this for our children.

A Thankful Bridgeport Family

We were so thankful for the respite. We have 4 children. We decided to send our son George to a typical preschool camp this summer. It was a perfect transition before entering the town preschool. He felt like his siblings going off to camp this summer.

A Greenwich Family

We want to thank you for our respite check. It has provided physical relief. My daughter is unable to support herself and she is very heavy. Being able to hire someone to help me with dressing, bathing, feeding etc allows me to stay strong in order to care for her in the long run.

A CT CYSHCN's Family

THANK-YOU FOR THE MONEY. IT GAVE US THE CHANCE TO RELAX AND NOT STRESS ABOUT NOT HAVING THE MONEY OR TIME TO EVER GO SOMEWHERE TO ENJOY LIFE. WE ENJOY OUR LITTLE BREAK SO MUCH.

A NEW BRITAIN FAMILY

Thank-you Thank-you I use it to pay for an afterschool program with other children for my son. It was really a wonderful thing.

A Windsor Mom

EASY FOR CHILDREN TO GO TO CAMP. IT SO HELP US WITH WHAT IT COSTS. IT WAS FUN TO HAVE SOME TIME JUST PARENTS WHILE CHILDREN AT CAMP.THANKS.

A NORWALK FAMILY

Thank-you for the check. It assisted me to bring my son to the amusement park and then my friend took him for me for a day and took him to the movies. I very appreciate it and thank you also because we bought him a bike to ride like other kids do.

A Plainfield Family

This check enabled myself and my husband to my son to camp where he could enjoy his summer with kids who don't have medical issues. It enabled us to do daily tasks without worry about his needs. It enable all of us to enjoy summer for the first time. We can't thank you enough and look forward to the next time we get help like this. This is the only help we have ever gotten for our family.

A Family from Hebron

This money helped us to send our kids to summer camp this year. Special camp is expensive and we were trying to make payments, but were just not up to date. When your check came it let bus make the last payment so both our children got to go to camp this summer. I hope we can get this again.

New Milford Family

With twins with autism summer is long and we just couldn't afford the type of camp they needed. Then your check came. Camp was great. We need to know how to get these funds again next year. Thankyou so much.

A Family in Gaylordsville

I had been waiting for these funds for a long time. It came just in time for my sons birthday. This made it possible for my son to have his first Chucky Cheese Party like many of the kids at school. I bought him books for his birthday. We also went on 2 family trips. One to Lake Compounce and one to Orchard Beach. This program was a blessing. I am still not working, but when he goes back to school I hoe to work again. Bless You.

A Hartford Family

When our house burned down and my daughter was burned I worried she would never enjoy summer again. When you helped me with these forms you gave me some information on a Burn Camp for children who had burns too. I never thought my daughter would go since we have so little money but you told me to call. She was accepted to go this year and you were right it was free, but she needed a lot of special stuff to go. Then your check came and we bought her all the supplies she needed to go. I just cried as she said goodbye and ran off with her new friend who had also been burned in a house fire. The child I got back at the end of the week was a new child! We can never thank you enough for the check and the information on the camp you gave us. It has really changed all our lives.

A New London Family

We took a family trip to 3 baseball games. I think my son now understands the game and so we bought him a bat and ball. I hope and dream that next year he will be able to play like the other boys on our street.

A Family in Woodbury

We were able to spend some awesome time together and enjoy life without worry of doctors, hospitals, illness or bills. It was really relaxing and brought us much closer together. The kids got to be just kids and had big smiles. We really appreciate this help so much! It really brought us together as a family together. We hope we will be eligible again soon.

Sterling Family

It helped my family so we can go places together and also my husband and I get a babysitter and go out alone first time since my son born 10 years ago. I wish all families get a chance like this. Money is hard but this was so big for us. Thank-you

A Family from Bridgeport

We were so thankful when we got this money. We went on line and all studied places we wanted to go. We vote, and we each pick a day trip. It made US A REAL FAMILY NOT PATIENTS FOR THOSE DAYS. We thank you so much. Please tell us what we need to do to get these funds again. It was a long time since we signed up and I don't remember what we need to do.

A West Hartford Family

This is the first time I got respite. It really helped for the better. I am going to school and also care for my son. This allowed me to hire someone to do fun things with him while I study so I do not feel guilty not to play with him. The time off was great. I really appreciate this program.

A Single Mom in West Haven

I am Mia's primary caregiver and I rarely get a break. We joined a pool and my husband will be taking Mia swimming while they bond. We have also picked a night a week that we will go to the pool as a family. This way our respite check will work for us for many months. We are so appreciative for this help which makes us feel like a regular family.

A Cheshire Family

I have not had a vacation since we had kids. With all their health issues we just don't leave them with anyone else. So we have decided I am going to get away with a friend and my husband will do the child care. Next time can be his turn. You asked how much we thought we would need a year. I think three checks like this. One for each parent to get away, and one for some family outings. But we appreciate what we got so much.

A Mom from Hamden, Ct

This has helped pay for care for my son. It is hard to find a camp or daycare to take him because he needs to take meds while he is there, but we found a day camp and also used his counselor to babysit a few times at our house. We really appreciate this. I do wish the processing time was less, it took almost a year to get this check and now I was told I have to wait a year to apply again. If I can help in anyway to make that happen faster, please let me know. Thanks

A Stamford Family

Thank you for the bonus check. I sent my son to a summer program that included Physical therapy and fun playing. This left me one on one time with my daughter. It really made our summer special. I wish I had found you sooner and look forward to getting funds again.

A Family from Branford, Ct

The Money I got was so helpful. We went as a family out to dinner and a movie a few times. We also got a sitter so we could get out as a couple alone. This was the first time we have left the kids since my son was born. It was very special to us. I Think this program is great. I was sorry to hear I can't get this every year, but it made such a difference to our family that we will be happy to wait.

Groton. Ct

I was able to take our family to Lake Compounce for a special day. WE just started my son on a gluten free diet so I was able to buy a special cookbook, and I did sing up for the food program you suggest because they do a special Allergy/ Gluten Free package. I can't thank you enough. Both the money and the information was invaluable. We have enough left for a parents night out for our anniversary.

No. Branford,CT

Thank you so much for the funds. It helped us take Katie on a great family vacation with horseback riding, swimming, and fishing. It was a blast. We all really enjoyed it.

A Westport Family

We got our check & used your suggested list of activities. We found a discount day at the indoor water park and had a great time. Another day we did the indoors mini golf which was really fun. You were right we found lots of great summer activities a reasonable prices which kept us cool and out of the sun. It was great to be a real family again. Can't wait till it is our turn for funds again.

Thomaston Family

It was great to get away. We used our funds for a weekend sitter so we could get away. As you suggested we asked her school aide if she would be available, and she loved the idea. Wish we could get funds to do this every few months. Our daughters needs are so intense and this is the only program we qualify for. Thanks

A Fairfield Family

Let me tell you I haven't gone out ever since my son got diagnosed with Autism. So I got a couple of babysitters and paid them while his father and I went out. Thank-you so much. I really needed this as we have been under so much stress lately. There is so much to learn when you have a child like this. I really needed a break for me. My son is like the energizer bunny, He just keeps going and going ad going. I can't say thank you enough. We need more programs like this so families can stay together and raise their special children.

New Haven, Ct

I WAITED SO LONG FOR THIS MONEY. IT ALLOWED ME TO TAKE MY KIDS TO THE BEACH BECAUSE I COULD HIRE SOMEONE TO GO WITH ME TO HELP WITH MY SON. IT WAS HIS FIRST TIME AT THE BEACH AND HE HAD A SMILE ON HIS FACE ALL DAY. I GOT TO RELAX AND IT WAS SPECIAL FOR ALL OF US. THE SECOND TIME WE WENT WE TOOK MY SON'S FATHER WITH US SO HE COULD SEE HOW HAPPY THIS MADE HIS BOY. WE WILL ALWAYS REMEMBER THIS SPECIAL SUMMER BECAUSE OF THESE FUNDS. WE BOUGHT A CAMERA AND TOOK PICTURES, THE ONLY ONES I HAVE OF MY SON. THANK YOU SO MUCH.

A BRIDGEPORT MOM

I used my check for camp for my son while I worked. This gave us funds to go on a family trip the end of the summer. I really appreciated this. All the other sources of respite we have gotten in the past have dried up.
Stratford, Ct

BOTH OF US WERE UNEMPLOYED THIS SUMMER. I DID GET A FEW HOURS AS A HOSTESS, BUT THAT WAS IT. WE WERE REALLY DOWN AND STRESSED. WHEN THE CHECK CAME WE PACKED UP THE CAR AND OFF TO GRANDMAS WE WENT IT ALWAYS HELPS TO BE HOME AND IT IS SO GOOD FOR MY KIDS TO SPEND TIME WITH THEIR GRANDPARENTS. THANKYOU SO MUCH. IS THERE ANYTHING ELSE OUR FAMILY CAN QUALIFY FOR IN THESE DIFFICULT TIMES?
A NORWICH FAMILY

We have had the worst year. Second child was given a diagnosis, my husband lost his job, and it seems like there is just no help out there for us. Then your check arrived. We tried to spread it as much as we could. We bought favorite foods and went on picnics as a family. We helped a school clothes swap that got us first pick at some clothes. We found an outside movie night to go to as a family. And we splurged and went to the new indoor water park for a special Autism event. We are holding money out so we can go to the next sensory free movie showing you talked about. We really appreciated all these breaks and a chance to be a real family even in these rough times.
Manchester Family

This allowed me to get away for a few days of R&R and know that my daughter was well taken care of. When I got back I spent the rest on a family dinner out and a movie. It was fun to be normal again.
Oxford, Ct

Stephen was able to be part of a toddler & Mom play group this summer and we also took swim lessons. It was great to be with other Moms and not worry about therapy, meds etc. We really thought a lot about how to spend this before we signed up for anything. This is a perfect program. Please don't go away or close down.
A Simsbury Family

WE USED OUR FUNDS TO GO ON A FAMILY VACATION. WE WENT TO AN ALL-INCLUSIVE RESORT TO TRY AND MAKE IT EASY FOR MY DAUGHTER. TRAVEL WAS HARD, BUT ONCE WE WERE THERE IT WAS WONDERFUL. I THINK THIS IS AN ENORMOUS HELP TO FAMILIES WITH SPECIAL NEEDS MEMBERS. OUR DAILY NEEDS ARE SO STRESSFUL AND WE REALLY NEED TO PLAN BREAKS IN, BUT WITH LOTS OF MEDICAL BILLS THE FUNDS ARE JUST NOT ALWAYS THERE. I AM GOING TO TAKE YOUR ADVICE AND LOOK FOR A SCOUT VOLUNTEER TO HELP IN THE AFTERNOON WITH KIDS TO GIVE ME A LITTLE BREAK AND GIVE MY DAUGHTER SOME SPECIAL ATTENTION. THANK YOU SO MUCH THIS IS A WONDERFUL PROGRAM FOR FAMILIES.
TRUMBULL FAMILY OF 5