Bring Our Children Home:

Improving Access To Home Nursing Services
For Medically Fragile Children







Coalition For Medically Fragile Children



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Executive Summary



When medically permissible and desired by the family, allowing medically fragile children to be cared for at home is best for their health and development. Children thrive both emotionally and developmentally in the care of a supportive family and the risk of infection is reduced for a child cared for at home.

Continuous home nursing services enable medically fragile children to be cared for at home. In multiple studies, home nursing services have been shown to be dramatically less costly than hospital care. Yet for many children enrolled in the Medicaid program, continuous home nursing care is not an option. Faced with woefully inadequate reimbursement rates, a growing number of medically fragile children in New York are unable to find the continuous home nursing services they need to be cared for at home. Even when everybody agrees that the child is eligible for the services and that it is better for the child and less expensive for the system for the child to be at home, families often cannot find nurses to provide the care.

New York should reduce expensive and inappropriate institutional care for medically fragile children in Medicaid by:

- 1 Increasing Reimbursement Rates for Home Nursing Services to Equal those Provided to other High Needs Medicaid Patients;
- Providing Case Management Services for Medically Fragile Children as a Covered Benefit Under the Medicaid Program;
- Creating a Demonstration Program Providing Comprehensive Care
 Management and Supportive Services to Medically Fragile
 Children; and
- Investing \$2 Million in Workforce Retraining Programs to Bring New Nurses into the Underserved Field of Skilled Home-Based Nursing Services for Pediatric Patients.

Available data suggest that the cost of these proposed changes would be cost neutral to the state Medicaid program, and could result in cost savings. These proposed changes will help ensure that children who can be cared for safely in their homes have that option, and that scarce Medicaid resources are spent on the most humane and appropriate care.



Background

There is an increasing need for continuous home nursing services for medically fragile children in New York's Medicaid program.

The care of seriously ill children has changed

The care of seriously ill children has changed dramatically in recent years. Innovations in medical technology and care are saving children's lives. As a result, there is an increasing need for nursing services to allow these seriously ill children to return to their homes.^{1,2,3}

Continuous home nursing services enable medically fragile children to be cared for at home. Continuous home nursing is regularly scheduled personal and skilled care provided by an LPN or RN, typically for extended periods (8-16 hours/day), to medically fragile children in their homes. The services are generally paid for by Medicaid or commercial insurance at an hourly rate. Continuous home nursing is the only level of service that can allow some children to return home. Children that are technology dependent, such as those with feeding tubes or on ventilators, and children with particularly complex medical regimens require regular, often hourly, procedures and interventions that personal care services workers and home health aides cannot legally nor practically provide. Typically, parents are intimately involved in the care of these children, shouldering 8-16 hours per day of their care. However, parents must sleep and work and care for other children. Without nursing services to support their children, parents are often left with no other option than institutional care.

When medically permissible and desired by the family, allowing children to recover at home is best for their health and development. Children thrive both emotionally and developmentally in the care of a supportive and supported family. 4,5,6 The risk of infection also is reduced for a child cared for at home. 7,8,9,10

Continuous home nursing services also can reduce costs. In multiple studies, home nursing services have been shown to be dramatically less costly than hospital care, with average cost savings ranging between 20 and 78%. 11,12,13,14,15,16

Yet for many children enrolled in the Medicaid program, continuous home nursing care is not an option. Faced with inadequate reimbursement rates and a nursing shortage, and without the benefit of case management services, it is increasingly difficult for children enrolled in Medicaid to find nurses to care for them in their homes. Current Medicaid rates for continuous LPN and RN services in New York are lower than the rates paid by commercial insurers and by Medicaid programs in many other states. Even within New York's Medicaid program, nurses caring for medically fragile children are paid less than when caring for other high needs patients, such as patients with HIV and AIDS. A shortage of nurses generally is amplified for medically fragile children, as programs to train nurses to care for this highneed and high-risk population simply do not exist. And despite the special challenges faced by lower income families on Medicaid, their children are not eligible for the case management services that currently help higher income families locate home nursing services through Medicaid's Care At Home Waiver programs.

The choice to care for a medically fragile child at home is a highly personal one, and it is not always possible for a variety of reasons. But when it is both desired by the family and medically appropriate, it is in everyone's interest to make care at home a feasible option for medically fragile children.

Example: A child having bone marrow transplantation is hospitalized for 21 days, then requires infusion therapy for 90-100 days. The infusion therapy can be done at home, but requires highly specialized services from a registered nurse (RN) on an hourly basis

Max's Story



Max Amar's mom, Rachel, wants more than anything to have him home with her. Yet he has only been home one day in his two and a half years.

Born with a small lower brain stem, Max cannot breathe or eat on his own. At 7 months of age, Max was given the green light to leave the Neonatal Intensive Care Unit and join his family at home. He was approved to receive 12-hours per day of care from a Registered Nurse (RN) through Medicaid. However, his family was unable to find an RN to provide the care. Under pressure to discharge Max from the hospital and eager to have him home, the family ultimately settled for someone with less training. It only took 6 hours for disaster to strike. Max's ventilator somehow malfunctioned and he stopped breathing. He was rushed back to the hospital where he spent several weeks in a coma.

Fearful that another disastrous episode with inappropriately skilled care could cost her son his

life, Rachel reluctantly has given up her hopes of having him at home with her for now. She is sure that the low rates paid to nurses in her area are a big part of the problem. "I live in Long Island, which is among the areas that has the lowest rates of nurses. I just can't bring him home - it's not safe without qualified nurses."

Currently, Rachel travels 2-3 hours a day from her home in Long Island to a pediatric rehabilitation hospital in Westchester County to visit Max. But even this arrangement is temporary. The rehabilitation facility does not provide long term care and Rachel has been told that the nearest appropriate facility for ventilator-dependent children like Max is in New Jersey. Today, she is desperately trying to find a care setting that will meet her son's needs and is near enough to her home so that Max can be a part of his family's daily life.

Nassau County, NY



Teddy's Story



The Burke family is thrilled to have their son Edward, a.k.a "Teddy," home with them. Teddy spent his first 5 months of life in the neonatal intensive care unit. Now almost 2 years old, Teddy requires home nursing assistance to monitor his oxygen and provide gastrostomy-tube feedings and medication.

Diagnosed with bronchopulmonary dysplasia and failure to thrive, Teddy has been approved to receive 10 hours a day, 7 days a week of home nursing through Medicaid. However, the family has only been able to find nursing care 5 days a week, usually the night shift, because there just aren't enough nurses who accept Medicaid's rates. "We have never been able to find enough nursing to fill all of the hours needed."

The lack of available home nursing care has been put a real strain on the Burke family. "Since there's no weekend nurse, the biggest impact has been a lack of sleep, when he was really sick we feared he may pull out his nasogastric and oxygen tubes, so

we couldn't leave him alone at all. There is no family time because my husband and I must take turns catching up on sleep." Teddy's mom, Cary, has had to take a leave of absence from her job because of the lack of home nursing, placing the family under financial stress.

Thankfully, Teddy's condition is improving. His nasogastric tube was removed recently, and his family hopes he will not require continuous home nursing much longer. But for now, the family struggles to keep him home and safe without the nursing care that he needs.

Ontario County, NY



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Proposal to Increase Access to Home Nursing for Medically Fragile Children

New York has recognized the value of avoiding institutional care for elderly populations and disabled adults. Similar efforts should be made to ensure that children are not left to languish in expensive and inappropriate care settings. The following four changes will significantly increase access to continuous home nursing services for children, enabling these children to be cared for in the safe and loving confines of their homes.

Increase Reimbursement Rates for Home Nursing Services to Equal those Provided to Other High Needs Medicaid Patients

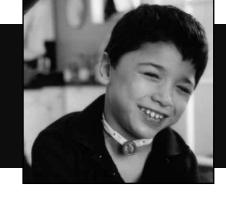
Reimbursement rates for continuous home nursing services for children enrolled in Medicaid are currently set by local departments of social services within a cap set by the New York State Department of Health. The rates for nursing services have increased only once by 3% in the last twelve years. Between 1993 - 2002 continuous home nursing rates were frozen. In 2002, rates were increased by 3%, a change that meant an increase in the hourly

rate for an LPN in New York City, for example, from \$23.00 to \$23.69.

While rates vary across the region, the rates paid for medically fragile children in New York's Medicaid program consistently are far below those paid by commercial insurers, Medicaid programs in other states and even rates for some other populations within the Medicaid program.

Hourly Reimbursement Rates for Continuous Home Nursing Services*							
	Pediatric Continuous Home Nursing Services under New York's Medicaid Program in New York City	HIV/AIDS Home Nursing under New York's Medicaid Program in New York City	Pediatric Continuous Home Nursing Services under Commercial Insurance in New York City	Pediatric Continuous Home Nursing Services under Medicaid in Other States ¹⁷			
LPN** RN**	\$23.69 \$27.81	\$36.80 \$46.93	\$35-50 \$55-70	\$25.47 - \$42.00 \$29.55 - \$50			

- * Rates represent total reimbursement to the nursing agency and include nurse wages and administrative costs.
- ** The level of care (RN or LPN) is determined by the complexity of the individual patient's condition and required care. For example, patients requiring intravenous infusions generally require care from an RN.



Given the well-documented nursing shortage, it is not surprising that the market for nursing care is highly sensitive to these rate differences. Once more, medically fragile children often have multiple, complex health needs that require sophisticated monitoring and intervention. The care these children require is high stakes and demanding. As children, they cannot offer guidance and oversight of daily tasks, and parents often are at work or sleeping during the time nursing services are assigned to the home. And just as a healthy child would suffer from having a new child care provider every week, medically fragile children need continuity in their nursing care to ensure their healthy psycho-social development. In short, it is a difficult job that requires a high level of professionalism. Families simply cannot compete in the tight nursing market for qualified nurses to provide the services that these children need to live safely at home.

Proposal: New York should require that rates paid for pediatric continuous home nursing services are no less than home nursing rates provided for any other population under the Medicaid program.

"If nurses can make more at a hospital or in an office, then why wouldn't they want to work there instead. If we could pay home nurses better then there would be better nurses and more of them." - Parent

Brittany's Story



Like all parents, Lisa Borgen believes her daughter is the "cutest little thing you've ever seen." And who could disagree. Eight year old Brittany loves bopping to her favorite music and spending time with her family. Brittany also has a complex medical history, leaving her prone to seizures and in need of multiple medications to treat various conditions. As a result, Brittany has been found to be eligible for continuous home nursing services through the Medicaid program.

Unfortunately, finding these necessary nursing services in the community is a constant struggle. While Brittany has been approved for 56 hours of nursing care a week, her family simply cannot find nurses to provide services. Currently, the family is relying on the assistance of a home health aide, and while they are grateful for the extra set of hands, it is no substitute for nursing services. "These aides work extremely hard, lifting patients and tending to their personal care needs, and for very low pay," says Ms. Borgen. But home health aides are not qualified to monitor Brittany's medical condition or to complete medical tasks that are a part of Brittany's routine care. So it is up to the Borgens to provide the care themselves.

The lack of available nursing has made the challenges of managing a household with a medically fragile child even more difficult. Unable to leave the home because of the fear of leaving Brittany alone with a lower skilled aide, it is hard to get out even to purchase necessary household supplies. The family also has suffered financially, as a regular work schedule is simply impossible.

The Borgens have been told by their home health agency that a nursing shortage and high turnover prevent them from having a nurse even though they are approved for one. This gives them little comfort. "Imagine you're a parent of a child with a disability and you just want to help your child, and you keep hitting a wall with no direction. This is what I feel like "

Nassau County, NY





Provide Case Management Services for all Medically Fragile Children as a Covered Benefit Under the Medicaid Program

Currently, medically fragile children who are in families with incomes too high to be eligible for Medicaid may obtain services paid for by the Medicaid program through the Care At Home Waiver Program. Among the covered benefits available through this program are case management services. Case management services assist families in coordinating the various services necessary for children with complex health needs to be cared for at home. Case managers also assist families in locating nursing services for eligible children. However, children in lower income families cannot participate in the Care at Home program and therefore cannot receive case management services.

All families, regardless of their income, face serious challenges finding nursing services for their medically fragile children. Lower income families, who lack case management services, also often are contending with lower educational levels, language and cultural barriers and difficult living environments that make finding care even more challenging. New York should provide all eligible children, including lower income children on Medicaid, the case management services that are necessary to help them to be cared for safely at home.

Proposal: New York should provide targeted case management services to Medicaid-eligible children who:

- are at increased risk for hospitalization or institutionalization, including but not limited to children who:
- are dependent on technology for life or healthsustaining functions,
- require complex medication regimens or medical interventions on a continuous basis to maintain or improve their health status, or
- are in need of ongoing assessment, anticipatory guidance or intervention to prevent rapid deterioration or complications that could place the child's life, health or development at risk AND
- are capable of being cared for in the community if provided with case management services and/or other services provided by the Medicaid program.

"It was very difficult to gain knowledge of the system and get set up in the beginning. There's no handbook, it's all just word of mouth." - Parent

Nicholas' Story



At the age of 6, Nicholas Geising's parents say he is a miracle. And with good cause. Diagnosed with pyruvate dehydrogenase deficiency, Nicholas has endured a history of heart and kidney problems, leaving him dependent on a ventilator to breathe, blind and wheelchair bound. Nevertheless, Nicholas "is an absolute joy to be around." He loves books and music and thrives on interacting with people, especially his little brother.

Although Nicholas has been approved by Medicaid for 80 hours of care from a Registered Nurse (RN) a week, the family holds no hope of getting that level of care. "It would be almost impossible to get an RN because of the lack of benefits and higher pay they can get in a hospital." The family has managed to cobble together about 40 hours a week from a Licensed Practical Nurse (LPN). Since the Geisings are not able to get evening shifts covered, Nicholas's mother, Angela, sleeps on a mattress on the floor next to him and his ventilator. As a result, she gets only a few hours of sleep each night.

Trained as a nurse herself, Angela is a willing and capable caregiver for her son. But the lack of nursing support has left her exhausted and overwhelmed. It has also taken a financial toll on the family. "Financially, it is killing us that I can't leave home to work. But I've been back to work a hundred times and every time Nicholas gets sick I have to give up my job and stay home."

Worn down by years of trying unsuccessfully to obtain qualified nursing, the Geisings have all but given up on getting the help that everybody agrees Nicholas needs. Still, they are grateful to have him at home and determined to keep it that way. "He is part of our family."

Wyoming County, NY



Create a Demonstration Program Providing Comprehensive Care Management and Supportive Services to Medically Fragile Children

Medically fragile children typically suffer from a variety of conditions that require specialized care from a range of healthcare providers. The complexity of their healthcare needs makes care coordination crucial. Yet for most children, the task of coordinating their clinical needs falls not to a trained healthcare professional, but to their parents. Parents report that they are often overwhelmed with the task and worry whether their children are getting what they truly need. An increasing body of research indicates that comprehensive care management services, designed to ensure clinical coordination of care as well as address the developmental and psychosocial needs of medically fragile children, not only improve their quality of life and care, it can actually reduce the overall costs of care.

Last year, New York passed legislation creating disease management programs aimed at improving care and reducing costs for adults with chronic illnesses. This year, the Governor has proposed a demonstration program which he has described as aimed at reducing the need for institutionalization of elderly New Yorkers through "creating incentives to providers to serve individuals with complex medical needs and supporting relatives and other caregivers to assist patients needing care at home." New York should build upon these initiatives to create a demonstration program targeted to medically fragile children. Funding for the demonstration program at \$3 million per year over three years would provide sufficient resources to serve a total of approximately 300 children in multiple demonstration programs statewide, as well as program evaluations.



"For the first 3 years, we didn't even know home nursing was available.
No one gave us information."

- Parent



Proposal: New York should create a three-year demonstration program providing comprehensive care management and supportive services to children who are Medicaid-eligible who:

- are at increased risk for hospitalization or institutionalization, including but not limited to children who:
 - are dependent on technology for life or healthsustaining functions,
 - require complex medication regimens or medical interventions on a continuous basis to maintain or improve their health status, or
 - are in need of ongoing assessment, anticipatory guidance or intervention to prevent rapid deterioration or complications that could place the child's life, health or development at risk AND
- are capable of being cared for in the community if provided with case management services and/or other services provided by the Medicaid program.

The New York State Department of Health should contract with no fewer than four home care service agencies, case management service providers, social service agencies, hospitals and/or other health care providers to provide access to a comprehensive array of clinical, developmental and psychosocial services to children to improve the quality and coordination of health care and avoid the need for hospital admissions or institutionalization. The total cost over 3 years would not exceed \$9 million and would be funded through the Medicaid program with federal financial participation. This allocation would cover the cost of all services, including care coordination, family supportive services and enrichment services for the child not currently covered through the Medicaid program. The Department would report back to the legislature on the impact of the program on the quality of life and medical outcomes for participating children and the overall cost-effectiveness of the program.

Joshua's Story



Joshua Sorcher is a bright and loving 5 year old with a heart-warming smile, which is all the more remarkable given all he endures. Joshua suffers from Cerebral Palsy and seizures. He cannot breathe or eat on his own and requires a gastrostomy tube for feeding and a ventilator. As a result, he requires constant care and supervision.

It was clear from birth that Joshua had serious medical issues. At three months of age, he was approved to return home, so long as his family had the help of a nurse. But the family was unable to find a nurse, and Joshua was instead discharged to another institution. While his family continued their search for nursing care, Joshua suffered a serious infection. It was then that doctors were forced to insert the tracheostomy tube to assist with Joshua's breathing.

Research has shown that children in institutional settings are at higher risk for infection, a fact that continues to haunt his family today. "If nursing was available, we would have been able to bring Joshua home at three months old instead of at 10 months. He probably would not have a trach tube now either. The trach tube makes him susceptible to tracheitis,

which puts him in the hospital every other month. It also keeps him housebound in the winter, because children with trach tubes can't go out in the cold."

Today Joshua is fortunate to get several hours of nursing care a day through private insurance - which pays nurses considerably more than Medicaid. He has been approved for an additional 6 hours of nursing care through Medicaid. But as was the case earlier in his life, this has proven an empty promise.

"Since he came home at 10 months old, I have used 25 agencies and called 80 looking for care. We can't find anybody to take Medicaid in the Bronx, because the nursing reimbursement rates are \$3.00 an hour less than Westchester County, which is close by." The family has resorted to hiring staff with no medical training, who they teach how to care for their child. The family pays for the help themselves, as Medicaid would not permit untrained workers to perform nursing tasks. But Joshua's parents say it is the only way they are able to continue to earn a living for their family while caring for Joshua and their other young child.

Bronx County, NY





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Invest \$2 Million in Workforce Retraining Programs to Bring New Nurses into the Underserved Field of Skilled Home -Based Nursing Services for Pediatric Patients

Providing quality nursing services to medically fragile children in their homes requires both a high level of technical competence and a fundamental commitment to the children in need of care. It is time to create specialized training programs to ensure that nurses are aware of this field of practice and are supported and encouraged to pursue it.

Proposal: New York should provide \$2 million to home care services agencies, health worker unions, general hospitals, and other health care facilities and educational institutions to address the shortage of trained personnel to address particular unmet clinical needs, such as homebased skilled nursing services for medically fragile children.



"Its a daily challenge for us to find and keep nurses."

<u>- Parent</u>

Estimated Proposal Costs & Benefits

Based on the best available data, it appears likely that the proposal to increase availability of home nursing services for the target population is cost neutral, and may have the potential to realize cost savings.

The projected annual cost for the proposal outlined above has been estimated by the authors to be approximately \$37.4 million per year. 18 This includes \$30.8 million for the increase in nursing rates, \$3.6 million for case management services and \$3 million for the comprehensive care management demonstration program. The increase in nursing rates assumes both an increase in payment for existing services and an associated increase in utilization due to the greater availability of qualified nurses.¹⁹ The cost of case management services assumes costs of approximately \$300 per month for 1,000 medically fragile children.²⁰ Because the workforce retraining proposal does not seek an additional allocation, but instead seeks legislative guidance on existing budgeted expenditures, this proposal is cost neutral.

A large body of literature has shown significant cost savings associated with the availability of continuous home nursing services for medically fragile children. Estimated savings have ranged from 20-78% of overall cost of care, depending on the health needs

of the target population and the nature of case management and nursing services provided. While accurate data about the average total health care costs for this proposal's target population do not exist, available data suggests that it is approximately \$124 million per year. Given that the cost of this proposal is estimated at \$37.4 million, a 30% decrease in the overall costs of care for this population would be required to fully offset the cost of this proposal. Thus, it seems likely that implementing this proposal would be at minimum cost neutral, and potentially realize cost savings to the New York State Medicaid program.

Of course, these estimates do not begin to address the costs and benefits to a range of other stakeholders in the proposed changes. The current cost to families in lost wages and personal hardship due to the lack of nursing services is not reflected. The current cost to hospitals who are unable to discharge children when medically appropriate because of a lack of nursing services also is not reflected. Most importantly, these estimates do not account for the countless direct costs to the children themselves - the emotional consequences of being separated from their parents and siblings, the physical suffering that results from inappropriate care, the impact of extended institutionalization on their psycho-social and intellectual development.

Conclusion

Home nursing services provide a lifeline for a relatively small but extremely vulnerable group of children in New York's Medicaid program. However, the value and reach of these services have been eroded over time by stagnant reimbursement rates and a lack of supportive services. These proposed changes will help ensure that children who can be cared for safely in their homes have that option, and that scarce Medicaid resources are spent on the most humane and appropriate care.

Megan's Story

Megan Overfield is a beautiful 7 year old, who despite her fragile medical condition, "just beams when you talk to her." Affected by mitochondrial disease, Lennox-Gastaut Syndrome and profound hypotonia, Megan receives home nursing services through Medicaid.

In order to assist Megan with her gastric tube feeding, multiple seizure medications and therapy for low muscle tone, the Overfield's have been approved for 35 hours of home care a week from a Licensed Practicing Nurse (LPN). However, as is all too common in their area of western New York, there are not enough nursing hours to be found. "It's a lot of work to find providers on our own, especially with the hectic schedule of a medically fragile child." As a result, the Overfields are usually only able to get between 12-15 hours of home nursing covered a week.

But even these hours are threatened when Megan goes into the hospital. Whether it is hospitalization for her annual seizure testing or just a bad case of pneumonia or the flu, to which she is susceptible, Megan usually loses her nurse when she is hospitalized. Megan's mother Mary, doesn't blame the nurses, "Medicaid won't pay for the nursing care while Megan is in the hospital and they must earn a living for their own families. But it makes

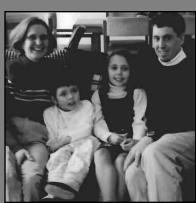
hospitalizations even more stressful when Megan can't come home when she is ready."

The Overfields have had to wait between 1-3 weeks to bring Megan home on occasion, simply because they could not find nursing care. This takes a toll on the family, as they must divide parents between a child in the hospital and other children at home. They also worry that the extra time in the hospital leaves Megan vulnerable to being exposed to other illnesses, a potentially life-threatening risk for a child with such fragile health.

The Overfields are committed to keeping Megan home with them. "She brings pure joy and unconditional love to our family." Yet they worry how they can continue to manage without the help that Megan needs.

Monroe County, NY





Endnotes

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- 17. Based on a survey of home health services provided for children in the following states: New Jersey, Pennsylvania, Nevada, Hawaii, California, Illinois and Massachusetts.
- 18. Precise figures for the number of medically fragile children in need of continuous home nursing services in New York and the current and potential costs of that care do not exist.
- 19. Estimates of current costs and utilization for continuous home nursing care were drawn primarily from 2003 Medicaid Reference Statistics data on children aged 0-20 in all Medicaid aid groups. Increased costs are based on current utilization and estimated increased utilization based on long run economic analysis of nursing supply and wage elasticity. Cost for children enrolled in the Care at Home Waiver programs were held constant, given that state expenditures are capped under this program. Data also was drawn from 2003 SPARCS records and the Bureau of Labor Statistics. Additional information used to inform coding and estimation was gathered from the academic literature, consultation with numerous experts in the field, and various government sources including CMS and the New York State Department of Health. Detailed methodological appendix available upon request from Melinda Dutton at Manatt, Phelps & Philips LLP.
- 20. It is assumed that approximately 1,000 children enrolled in Medicaid and not in the Care at Home Program are medically fragile and would be in need of case management services. This number was derived from the Medicaid Reference Statistics in consultation of 2003 SPARCS data and other sources.
- 21. See United Hospital Fund, High Cost Medicaid Patients: An Analysis of New York City Medicaid High Cost Patients (March 2004) available at www.uhfnyc.org in which the cost for the highest 1,595 children (representing 3% of disabled children receiving Medicaid) was found to be \$173 million in 1999. Adjusted for inflation, this figure can be conservatively estimated at \$208 million. Adjusted proportionate to statewide expenditures and enrollment, the cost is approximately \$335 million for 2,700 children. We assume for the purposes of this study that 1,000 children would benefit from the policy changes proposed. The proportionate cost for 1,000 children is \$124 million.



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For more information about the Coalition for Medically Fragile Children or this report contact Melinda Dutton at 212-790-4522 or Jim Lytle at 518-432-5990.

Coalition For Medically Fragile Children

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