



New York State Academy of Trial Lawyers

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Comments on The New York Medical Indemnity Fund Proposed Amended Regulations

Introduction

On behalf of the NYS Academy of Trial Lawyers and myself, I am writing to comment on the proposed amendments to the New York Medical Indemnity Fund and urge that these proposed regulations be withdrawn. I am a practicing attorney, and I have studied both the Fund and its regulations. A number of families who have children in the Fund have shared their experiences with me, and therefore I am very familiar with how the Fund operates and how it has treated families since its inception. In 2012, I co-authored a law review article which extensively analyzed the Fund's enabling legislation, as well as what, at that time, were the "Emergency Regulations" under which it was operating.¹ Unfortunately, shortcomings of the Fund, and the difficulties it would impose on these severely disabled children which were predicted in that article, have been more than borne out. The Fund has made life unnecessarily difficult for these families—especially when compared to the compensation that was taken from them to create the Fund. It is respectfully submitted that the currently proposed amendments to the Fund regulations—by further unnecessarily restricting access to care and refusing to approve necessities which would provide therapeutic benefit and improve the quality of life of these severely injured children--will

¹Kessler and Fahrenkopf, *The New York State Medical Indemnity Fund: Rewarding Tortfeasors Who Cause Birth Injuries by Rationing Care to Their Victims*; 22 Albany Law Journal of Science and Technology 173; <http://www.albanylawjournal.org/Documents/Articles/22.2.173-Kessler-Fahrenkopf.pdf>

make a bad situation even worse for the families who have been forced into obtaining services from the Fund.

The more than three hundred children now enrolled in the fund require extensive care, equipment, and services, and the effort required by their families to maintain these children twenty-four hours a day is already enormous. These families deserve our support to make their lives easier-- especially since they were forced by law to give up the compensation which would have enabled them to obtain the services themselves-- instead creating more obstacles to get the Fund to pay for necessary services and equipment. The proposed amendments to the regulations will make it more difficult to get the care that the children in the fund were promised, and to which they are entitled.

Because I have written about the Fund,² I am regularly contacted by parents of children who suffered neurologic impairment at birth, concerning their experiences in attempting to get the medical care, equipment and services that their children require to maintain their health and improve their quality of life. Based on my conversations with a number of parents, not only is the Fund depriving these children of what they need, but the hurdles imposed by the Fund and the effort required by these families to get even basic services is overwhelming. It is not an exaggeration to say that – without exception – every parent of a Fund child with whom I have spoken over the last several years has used the same one word to describe their Fund experience.

² See e.g.

<http://www.rrkslaw.com/Articles-Appearances/Obamacare-and-the-New-York-Medical-Indemnity-Fund-Where-is-the-Outrage-over-Rationing-Care-to-Innocent-Children-Injured-by-Negligent-Doctors-and-Hospitals/>

<http://www.disabled-world.com/news/america/newyork/indemnity-fund.php>

<http://www.rrkslaw.com/Articles-Appearances/Disabled-Individuals-Cared-For-by-New-York-State-A-Preview-of-Care-under-The-New-York-State-Medical-Indemnity-Fund/>

<http://www.rrkslaw.com/articles-appearances/new-yorks-death-panel-lottery-for-children-injured-by-medical-malpractice-at-birth/>

<http://www.rrkslaw.com/Articles-Appearances/The-Double-Secret-New-York-Medical-Indemnity-Fund-Where-is-the-Information-About-Fund-Operations-and-Where-are-the-Hearings-and-the-Fund-Regulations/>

<http://www.rrkslaw.com/Articles-Appearances/Challenging-The-New-York-Medical-Indemnity-Fund/>

Each one of them calls it a “nightmare.”

The new proposed regulations will unfortunately further restrict the care and equipment that these children will receive, lower the amount that the Fund will pay for services, and make the process to obtain equipment and improve handicapped accessibility even more burdensome than it is already. This Memorandum will briefly explore the impact of some of the proposed amendments.

Background

In addressing the impact of the proposed Fund regulation amendments it is important to recall why the Fund was created and what it was promoted to do by its advocates and, indeed, what persons not familiar with its day to day operations may believe that it is accomplishing.³

Unlike, for example, workers compensation, which applies to all workers injured on the job without regard to the fault of the employer, the Fund is *not* universal to all children who suffered a neurologic injury at birth. To the contrary, the Fund *only* applies to that small number of children who were injured at birth *as the result of the proven medical malpractice* by a doctor or hospital. In order for the Fund to apply, these children must go through all the steps of malpractice litigation, and then *only* after they have either proven and obtained a verdict and judgment against a defendant confirming the deviations from accepted care *and* that such malpractice caused the neurologic injury, or they have convinced a defendant to settle their malpractice claim, does the Fund apply.

³ Among the promoted purposes of the Fund when it was enacted was the hope that it would reduce medical malpractice insurance costs by prohibiting children injured at birth from recovering damages for the cost of future care from the hospital or doctor who caused the injury that required care. Whether or not the reduction in medical malpractice insurance costs has been achieved is questionable, but well beyond the scope of these comments. However, one consequence of the Fund is indisputable: Assuming that the cost of future care for birth injured children is reduced by the Fund paying for it instead of the charging the negligent party who caused the injury, that cost reduction can *only* occur by either limiting (rationing) the amount of care, equipment and services that the child receives, or reducing the amount paid for it—which limits access to qualified providers-- or both. Unfortunately, that is exactly what has happened and the situation will be exacerbated by the proposed amendments to the regulations.

At that point, even after obtaining a verdict against the negligent defendant which establishes what future care is required and provides for a sum of money to be paid in installments into a trust to provide for the child's future care needs, the defendant's obligation to pay for that amount is extinguished, and the child is forced into the Fund which, using taxpayer money, is supposed to pay for his or her care.

Thus, even with a judgment against a defendant to compensate the child for the cost of future care, the child receives absolutely no compensation for this proven loss. Nor does the defendant pay any money into the Fund. This scheme is unique among any other malpractice or other tort victim in New York and, indeed, to my knowledge, any tort victim in the United States. It takes away an otherwise enforceable judgment against a defendant after it has been rendered, and in its place requires enrollment in the Fund which is supposed to pay for future care needs. The Fund is not bound by the Court determination of the amount required for future care or the services that the Court had found were required for the child's well-being. Rather, the child must get the Fund to approve the services that it will pay for under a time-consuming and burdensome administrative process. And, if the Fund denies a service, the appeals process is not only difficult and weighted against the child, but time-consuming and expensive. After enduring a successful malpractice litigation, these families are forced into a lifetime of haggling and/or litigating against the Fund, to recover a portion of what was decided necessary in their lawsuit against the tortfeasor.

It would seem that depriving a person of the right to collect a judgment would create a serious constitutional question concerning the taking of a property right,⁴ especially, as has proven to be the case, the Fund is not an adequate replacement for the right to the enforce the judgment that has been destroyed by statute. Having been created and promoted as a substitute to provide the

⁴There are a number of other serious constitutional issues raised by the Fund. See, Kessler and Fahrenkopf, *The New York State Medical Indemnity Fund: Rewarding Tortfeasors Who Cause Birth Injuries by Rationing Care to Their Victims*; 22 Albany Law Journal of Science and Technology 173 (2012).

care that would have been paid for by the judgment that has been taken away, it would seem that the Fund's (New York State's) obligation to pay for care should be interpreted in the light most favorable to the child's needs. It would appear that such was the Legislative intent. Indeed, the Regulatory Impact Statement of the Department of Health at the time that the initial Fund regulations were proposed stated that "subdivision 3 of section 2999-h of the PHL sets forth a broad definition of "qualifying health care costs" for services and supplies" and gives the Commissioner of Health authority to further "define" such "qualifying health care costs" by regulation. It does not give the Commissioner the right by regulation to significantly *restrict* such broad definition of "qualifying services." Unfortunately, however, not only do the current regulations fail to comply with what should be the "broad" definition of the services which the Fund will provide, but the proposed amendments create even more onerous restrictions. They further limit care and equipment, and increase the burden on the families of Fund children. As such, they are inconsistent with the purpose of the legislation that created the Fund.

The Proposed Amended Regulations

Based on my conversations with families, their experiences with the Fund has been universally frustrating and unpleasant. It must be kept in mind that taking care of a severely disabled child with cerebral palsy, as most of the Fund enrollees are, is a full time job, even if nursing or respite care is available. The Fund has made the process by which it processes and evaluates requests for services into a maze which even highly educated and sophisticated parents cannot navigate successfully. For less sophisticated caregivers, the Fund has made the process nearly impossible.

The burden of constant applications, requests, compliance, documentation, Fund denials, resubmissions, and appeals makes the already challenging lives of these families even more

difficult – and that is when the family is successful in obtaining the requested services. When they are not, these children are forced to go without. One mother told me recently that dealing with the Fund consumes upwards of twenty hours of her time a week, or more.

By its own Regulations (§69.10-4 (3)-(8)), the Fund is required to provide a “case manager” who is required to establish a “comprehensive case management plan to assist the enrollee to manage all qualifying health services needed by the enrollee... “to assist... the enrollee... to obtain the services set forth in the... plan,” and to “assist... the enrollee with any forms necessary.” None of the families with whom I have spoken have *ever* received such a plan, or gotten the required assistance. The “case managers” are geographically remote, usually located out of New York State, and have never even seen or otherwise evaluated the child whose care they are supposed to be coordinating. Rather than acting as a “case manager” advocating for necessary care and finding it, their role appears to be to serve as a gate keeper to restrict care and save money.⁵ Indeed, at least one parent quoted their case manager as saying that she was specifically told that keeping her job was dependent on denying their application for a requested item of care. So these families are left on their own to find caregivers, equipment, and contractors. Their experience with the Fund consists of begging for services or approvals, and fighting denials. They must contend with an army of Fund and Health Department employees who seek to limit the services that these families receive.

⁵ The Case Management Society of America’s Standards of Practice requires “recognition” that a case manager’s “primary responsibility is to his/her clients,” and also that “[t]he case manager should advocate for the client at the service-delivery, benefits-administration and policy-making levels.”
<http://www.cmsa.org/portals/0/pdf/memberonly/StandardsOfPractice.pdf>

Similarly the Commission for Case Management Certification requires that “[c]ase managers’ first duty is to their clients – coordinating care that is safe, timely, effective, efficient, equitable, and client-centered.”
<http://stage.cmbodyofknowledge.com/content/case-management-knowledge-2>

The “case managers” employed by the Fund do not appear to be acting in accordance with these well-established ethical requirements for professional case managers.

The current Regulations are far more restrictive in providing services and equipment than could have been envisioned when the Fund was created by the Legislature. Unfortunately, the proposed amendments make the situation worse. Here are some examples.

Assistive Technology

Although the description of the amendment to what constitutes “assistive technology” (§69-10 (b)) euphemistically asserts that it is to “clarify” which items will be covered by the Fund, the true impact is to severely limit what they will provide. Under the current regulations an assistive device will be paid for if it is “determined necessary by a physician for purposes of... *habilitation, ability to function, or safety* in his or her current or desired residence.” The amended regulation, in contrast, now allows a device *only* if it “is essential for activities of daily living” and now specifically *excludes* anything that is used for recreational or therapeutic purposes. Moreover, under the amended regulations, the Fund will not approve anything that is not designed specifically for a person with a disability or which would be useful in the absence of an injury.

The scope of this proposed restriction is breathtaking. *A severely disabled child will now no longer be entitled to obtain equipment which provides therapy or recreation to her.* So, for example, under this definition, a child who cannot play with traditional toys is prevented from getting special switch operated toys designed for the handicapped, and which are necessary for both therapeutic purposes (switch activation for controlling her environment) as well as enjoyment.

One mother recently told me that her son is able to activate toys only through special sensory switches. These “toys” provide occupational therapy to improve function so that someday he may be able to use learning and recreational toys independently, and thereby improve his ability to control his environment. The proposed amended regulations will not cover these assistive

devices because they are therapeutic and recreational in nature, and not essential for activities of daily living. Similarly, this same child requires a Bluetooth switch that can be used to access an iPad with special needs applications. Since the Bluetooth device is for therapeutic and/or recreational purposes, and is not specifically designed for a disabled person – and, even though the applications are designed for the disabled – the switch would not qualify under the amended Fund regulations.

Environmental Modifications

Similarly, the asserted purpose of the proposed amendment to home modifications is to “clarify” what items will be approved. In fact, the purpose is to exclude significant categories of home modifications, and also to limit the purposes for which modifications will be provided by the Fund.

The current regulations (§69-10.1(m)) define an “environmental modification” as an “interior or exterior physical adaptation to the residence where the enrollee lives that is necessary to insure [his] health welfare, and safety... [and] enables him... to *function with greater independence in the community and/or helps avoid institutionalization...*” The proposed amended regulation eliminates “function with greater independence in the community” as a legitimate purpose of home modification. Instead, they seek to limit modifications for the benefit of these children *only to those that enable “activities of daily living.”*⁶ Therefore, home modifications to allow access to recreation, those that are therapeutic, or which enhance quality of life, are excluded.

⁶Activities of daily living are limited to “basic self care tasks such as dressing and undressing, self feeding, bowel and bladder management, ambulation... communication... functional transfers... and personal hygiene and grooming.” (§69-10.1 (a)). Thus anything that is therapeutic, improves function, or quality of life, or is recreational, therefore, is not for an activity of daily living, and therefore prohibited.

The proposed regulations prohibit any modification that adds square footage or even renovations to an existing home if its purpose is for “providing therapy.” The list of items that are *not* covered under the proposed amended regulations, even if they are important, include elevators (even if that is the only means of accessing the home); intercoms (even if that is the only method of communication from a child who is not mobile); fencing and security gates; and even bathtubs necessary for aqua therapy.

One quadriplegic cerebral palsy child’s family requested but was denied a large inside bathtub in order to provide aqua therapy which was ordered by a physician as essential to moving the child’s otherwise immobile limbs. The only alternative source of providing the required aqua therapy was at a rehabilitation center many miles away, and was only available during school hours. This would have required pulling the child out of school frequently, driving many miles, undressing him and redressing him (no simple task with a child with this disability) and then returning him to school. The Fund would presumably pay for the aqua therapy sessions – at a much greater ongoing cost than providing a tub – but not for the tub itself, which not only would have saved money but improved the child’s education and quality of life, and decreased the challenges to his caregiver.

A client of mine has a hypoxic brain injury, and though almost fifteen years old, is functioning at the level of a five year old. He cannot be left unsupervised. Yet, the proposed amended regulations will prohibit payment for fencing and a security gate so that he could be allowed to safely play outside in his yard without an adult being present at all times to prevent him from wandering into the street.

Many children with these disabilities are quite temperature sensitive, and require a constant environment within limited temperature ranges and often times air filtration. For them air

conditioning is not a luxury but a medical necessity, and having it in a home may prevent the need for institutionalization. Yet the proposed regulations prohibit this item. Similarly, many of the Fund children require constant access to electrically powered medical appliances, in some cases as a matter of life and death. Yet the proposed amended regulations prohibit upgrades to a home's electrical system unless it is *solely* to provide power to these medical devices. One family whom I know was denied a backup generator to power life critical equipment because it would have served the entire house. Apparently to the Fund, the child's equipment are not allowed to move within the house, or a separate circuit for his equipment could be added and his caregivers would be required to try care for him in the dark even if the equipment remained functional.

The proposed amended regulations also prohibit adding square footage to an existing home. One family who contacted me had a home with a small garage which would only fit a compact car. It would not fit a handicapped van, which the family required for their child's wheelchair. The Fund denied their request to increase the size of the garage to accommodate the van. This requires the family to stand outside to get the child and his wheelchair out of the van in the cold, rain or snow, and expose him to the elements.

Caring for a quadriplegic child requires an enormous amount of specialized and sometimes bulky equipment to keep them functioning. Even if the Fund may pay for the necessary equipment, many of these families have no place put it. Yet the proposed amendments – even where square footage is not increased – *prohibit “renovation of existing rooms... for the purpose of providing therapy, training, education or storage.”* Under the proposed amendments, therefore, a family cannot increase the square footage of an existing residence to provide for room for necessary therapy, training, education and storage, yet neither can they make renovations to that existing structure to provide for such necessities. I have seen many “dining rooms” that are no longer

usable by the family because they have become only the storage place available for such essential equipment.

Another family whom I know was denied a wheelchair accessible path to enable access to the backyard, resulting in the child being stuck inside when at home. A recent decision by the Fund—approved by the Commissioner of Health denied yard modifications necessary for wheelchair access, simply because they were outside. The current regulations (§ 69-10.1 (m)) defines an “environmental modification” as

an interior or *exterior* physical adaptation *to the residence in which an enrollee lives* that is necessary to ensure the health, welfare, and safety of the enrollee, *enables him or her to function with greater independence in the community....* (emphasis added)

Unbelievably, the “exterior” modifications that “enable[d]...her to function with greater independence in the community” was denied by the Fund, and the denial was approved by the Commissioner of Health. In the decision denying the wheelchair accessibility they wrote that modifications are limited

“to the residence *in which* the enrollee lives. *The enrollee does not reside in her backyard. Her residence is her house.*” (emphasis added)

The proposed amendments to the regulations seek to codify this tortured interpretation and thereby cruelly prevent those home modifications to enable use of the exterior of a home by a disabled child.

The proposed amendments also prohibit modifications to the basement of a home – and even modifications to provide *access* to a basement unless “such access is necessary for an enrollee for an activity of daily living...” Apparently the Fund does not consider therapy or recreation, or simply being able to access the entire house to be with the rest of the family to watch TV or engage in other activities, to be very important. The enrollee will simply not have access to

the entire premises under the proposed amended Fund regulations.

Respite Care

Providing care to a quadriplegic child is a twenty four hour a day – seven day a week job. The level of burnout and stress on these families is enormous. Although the Fund does recognize respite care as appropriate, the proposed regulations place new and unreasonable restrictions on it. Respite care is limited to twenty hours per week (1,080 hours per year). However, the proposed regulations eliminate the possibility of respite care for “substitute care... because the caregiver [parent] is not at home because of work or school.” This adds to the difficulty of the parent to become employed and imposes an additional significant economic hardship on these families. Implicit in the regulations is the unfounded assumption that families alone have the unpaid responsibility to provide full time care even to adult enrollees, and that a primary caregiver is precluded from becoming employed to support themselves or their family.

In addition, the proposed amendments provide that “respite care may not be provided by a relative or member of the household.” Thus, family members – grandparents, aunts, uncles – the people other than parents who are most familiar with taking care of the disabled child’s needs – cannot be paid for respite care. Instead, the caregiver must find a stranger, with limited knowledge of caring for the child, who is available – often on short notice – and willing to undertake this responsibility for the Medicaid rate of reimbursement. (See below). It is my understanding that even Medicaid does not impose this restriction on close relatives providing paid respite services.

Exterior Physical Adaptation

A new definition is proposed for “exterior physical adaptation” which is authorized only if it is to provide two accessible entrances to the premises. The new regulation excludes coverage, among many other things, to “modifications to an existing driveway... or improvement of a

walkway that is not necessary for entrance into or exit from the home.” This language appears to seek to codify the unreasonable determination described above whereby it was found that because a child “does not reside in the backyard,” she cannot get modifications to enable her access to it.

One family who contacted me had requested approval for a slight change to the grade of a driveway – which because of the length and configuration of the wheel chair van – was damaging its undercarriage and lift mechanism. This would be prohibited under the proposed amendments. As noted above the family who requested alterations to an exterior backyard walkway to make it wheelchair accessible so that the child could utilize the backyard with the rest of the family would be prohibited under the proposed amendments.

Approval of Home Modifications and Assistive Technology

In addition to the already extensive process for Fund approval of home modifications or assistive technology, the proposed amendments create an entire new level of complexity that almost no parent – much less a parent who is providing care to a severely disabled child twenty four hours a day – could navigate by themselves. The process requires hours of time and extensive consultation with professionals – architects, rehabilitation professionals, and construction contractors – in order to even apply for these services, often at great personal expense to the parents of these children. One family who contacted me submitted a detailed fifty page report from a rehabilitation professional to support their application for home modifications, only to see it largely rejected. Another family told me that they have had to retain a rehabilitation professional at their own expense to prepare their application. The process needs to be simplified, not made more challenging, and the Fund needs to provide help in getting these services – as it is required to do by its own regulations (§69-10.4) – instead of imposing more roadblocks.

Rates of Payment

This is a critical issue which has a significant impact on the health and well-being of children in the Fund. The statute creating the Fund (PHL §2999-j) specifically provides that private physicians shall be paid at one hundred percent of the “usual and customary rates.” Yet the regulations and the proposed amendments provide for physician payments at the “eightieth percentile of the usual and customary rates for private physician services.” I do not understand how this is consistent with the statute. I have had families tell me that their regular physicians will not accept these rates and thus their children’s access to medical care is compromised.

Even more concerning is the rate of payment for other than physician services at the “Medicaid rate.” Even when nursing care is approved, for example, it is almost impossible to get qualified providers to work at Medicaid rates. One family told me, for example, that they are approved for care aides by Medicaid forty-four hours per week and extra seven hours per day while their child is not in school. At the Medicaid rate of \$11.99 per hour, they are fortunate to get aides for twenty hours a week. Because of the child’s care needs, the aides need a nursing or special needs background and they cannot just hire a babysitter. The otherwise approved hours are left unfilled. Many other families on have shared similar experiences. By precluding a “relative” from providing paid respite services, the proposed amended regulations exacerbate this situation.

The same is true of other services. For example, I was contacted by the family of a child who, for a number of medical necessity reasons, required various enhancements to his eyeglasses at a cost of almost \$250.00, which his mother paid out-of-pocket. She was initially reimbursed at the Medicaid rate of \$16.00 before complaining and was eventually being reimbursed the cost.

Nor do the unreasonably low rates of pay to providers merely limit the services that these children can get. They have the significant potential to adversely impact their health and even longevity. Even if the plaintiff is fortunate enough to acquire providers at Medicaid rates, then the issue is whether the quality of care would be sufficient for the plaintiff's needs. A number of studies and articles confirm the fear that Medicaid rates will compromise access to the care that these vulnerable children (and adults) require. A 2011 study published in the *New England Journal of Medicine* established that Medicaid patients (the equivalent of Fund enrollees, since reimbursement for most services are at Medicaid rates) experienced significant delays in getting appointments with medical subspecialists as compared to private pay or private insurance company patients. The delay in getting appointments was about twice as long—an average of forty-two days under Medicaid—compared to twenty days with private insurance.⁷

When care is restricted and inadequate there is legitimate concern that these children may suffer unnecessarily, and likely die prematurely.⁸ It is hardly surprising therefore, that investigative reporting discovered that borne out by developmentally disabled individuals. The *New York Times* article cited describes a number of unexplained deaths and other injuries to disabled individuals in state facilities, most of which apparently related to poor care, such as choking and drowning. The *Times* reported “the average age of those who died [from] unknown causes was 40, while the average age of residents dying of natural causes was 54.” The State Commission on Quality of Care and Advocacy for Persons with Disabilities found that there had been “concerns about the quality of care in nearly half” of the unexplained deaths. The

⁷ Bisgaier & Rhodes, “Auditing Access to Specialty Care for Children with Public Insurance,” 364 *New Eng. J. Med.* 2324, 2325, 2328 (2011); Harrington et al., “Nursing Staff Levels and Medicaid Reimbursement Rates in Nursing Facilities,” 42 *Health Services Res.* 1105, 1106–07 (2007).

⁸ See e.g. Kessler, “Critical Analysis of the Life Expectancy Research from an Attorney’s Perspective,” in *Pediatric Life Care Planning and Case Management*, (797–799) (Susan Riddick-Grisham ed., 2004); Hakim & Buettner, “In State Care, 1,200 Deaths and Few Answers,” *New York Times*, Nov. 5, 2011, at A1, available at <http://www.nytimes.com/2011/11/06/nyregion/at-state-homes-simple-tasks-and-fatal-results.html>

“unexplained” death rate for individuals cared for by the State of New York was more than four times higher than the rate in Massachusetts and Connecticut.

Thus even if the Fund were to approve nursing care for a certain number of hours, as noted, it is likely that the family would be unable to find nursing staff who would be willing to work in the home at those rates or on all shifts. The same is true with necessary equipment, and certain providers, particularly those who provide more expensive or higher quality equipment, may refuse to provide their goods at Medicaid rates—all of which has the significant potential to compromise the health and well-being of these children and their caregivers.

Cost to Regulated Parties

The proposed amended regulations assert that “there are no costs to regulated parties by these regulations. Qualified plaintiffs will not incur any costs in connection with applying for enrollment in the Fund or coverage by the Fund.” That statement is simply untrue. Even a cursory review of the regulations as they exist presently – and made worse by the proposed amendments reveal there are tremendous costs to families – both out- of-pocket and in the time and energy expended to try to obtain benefits. One mother estimated to me recently that, in addition to providing full time care to her child, she spent on average more than twenty hours a week dealing with Fund issues, making it impossible for her to get even a part time job. Based on my discussions with a number of families, this mother is not unique, and who knows how many families just give up because of the difficulties in getting services and payment from the Fund. If a family appeals the Fund’s denial of a service or item, they incur significant cost in time and likely require legal counsel at significant expense in order to pursue the appeal. The appeals process is anything but user friendly and the Fund families consider it so stacked in favor of denials that they often just give up rather than pursuing an appeal.

Consumer Advisory Committee

The Fund enabling statute (PHL §2999-j (16) requires the Commissioner to “convene a consumer advisory committee for the purpose of providing information, as requested by the commissioner, in the development of the [Fund] regulations...” I do not know if such a consumer advisory committee exists and, if so, who serves on it, or whether the Commissioner ever requested any information from the Committee about the proposed amendments to these regulations. Certainly none of the parents to whom I have spoken are aware of any such committee, and it is difficult to believe that any reasonable consumer advisory body would be in favor of either the proposed amended regulations or the way these families have been treated even under the current regulations.

Suggestions for Improvement

Based on my discussion with many families over the last several years, it is clear the Fund is not meeting the needs of these children and their caregivers. The process to obtain services is overly and unnecessarily complex, and the rates of payment are inadequate for these families to obtain the services and equipment that these children require. It certainly does not provide an adequate substitute for the right to recover damages for future care pursuant to a judgment so that parents can make health care decisions and provide for their child’s needs.

The Fund regulations (§69-10.4) require that enrollees be provided with a qualified case manager who will prepare a “comprehensive written management plan to assist the enrollee... to manage the delivery of all qualified health care services... and also to assist the enrollee to obtain those services and filling out the forms necessary to obtain payment.” However, based on my discussion with a number of families, the case managers are geographically remote, they are not

qualified or even aware of the child's needs or services available to these families, and they have not fulfilled their obligation to provide the comprehensive case management plan.

The Fund needs to provide better services to these families. As a start, they should be required to comply with §69-10.4, but more importantly, since the Fund and its contractor's employees primary role seems to be denying payment for services, the Fund should be required to create an ombudsman at the Fund's expense whose sole role is to advocate on behalf of these children for necessary services within the Fund. This ombudsman should not be employed by the contractor but rather should function independently and answer only to the enrollee and his or her family—as the ethical standards for professional case managers require.

In addition, consistent with the Legislative intent that the Fund serve as an adequate substitute for the money judgment or settlement that was taken away from these children, the Regulations should be amended to assure that “qualifying health care services” is “broadly” interpreted, as was stated at the time of the initial adoption “Emergency” regulations. Specifically the regulation should provide that services, equipment or ordered by a child's physician or other professional are presumptively valid, both initially and in any administrative or judicial review proceeding, and the burden should be on the Fund to overcome that presumption to deny a service or item.

There are other remedial measures that would help to level the playing field, and assure that these children have access to the care, equipment and services which they require. These might include penalizing the Fund or its contractor for an unreasonable delay or denial of services, and enhanced and more available judicial review. Legislative action may be necessary to make these changes.

Conclusion

The Fund is not adequately meeting the needs of the children covered by it. It overly and unfairly restricts what it will pay for, and the process to get approval is much too difficult and expensive for these families to navigate—particularly when the deck is stacked against them. The proposed amendments to the regulations make a bad situation worse – much worse. It is respectfully urged that the proposed amendments be withdrawn, and that the regulations be fixed to better meet the needs of these families, as the Fund was intended to do.

Respectfully on behalf of the NYS Academy of Trial Lawyers,

MICHAEL W. KESSLER

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