

“Birth and Betrayal” Miami Herald Series Correcting the Record about NICA

Claim: NICA routinely denies requests for equipment repairs and replacements.

The Truth: Since the program’s inception, NICA has paid over \$35 million for equipment, supplies, and other related expenses. However, because NICA is the payer of last resort, when it has denied a request for equipment repair or replacement, it has typically been due to delay or lack of medical documentation from the doctor, equipment providers or insurers.

Claim: \$100,000 initial payment is woefully insufficient.

The Truth: NICA agrees and wholeheartedly supports SB 1786 and HB 1165, which would raise the amount from \$100,000 to \$250,000 and then increase it annually to keep up with growing costs. Also, the initial cash payment is not intended to cover the care of a severely brain-damaged child. It is a cash distribution, followed by NICA paying for all medically necessary and reasonable requests. The average NICA family receives approximately \$4.9 million in total benefits during their child’s lifetime.

Claim: Parents were not told about the at-home care reimbursement option.

The Truth: NICA currently pays 78% of active families for at-home care. NICA paid \$3.3 million directly to parents to care for their children during the first quarter of 2021, and over \$110 million since the program’s inception. Parents now are told at the initial orientation meeting with the nurse case manager and receive a follow up letter with a copy of the Benefit Handbook and a reminder to review carefully for the specific needs of their child.

Claim: NICA declined to meet directly with the Miami Herald.

The Truth: NICA has complied with all of the Miami Herald’s requests that have not included personal health information, which would violate HIPAA. In total, NICA provided tens of thousands of pages of documentation in response to public records requests and responded to over 100 specific questions posed by the Miami Herald.

Claim: Families were cheated out of benefits.

The Truth: The average NICA family receives approximately \$4.9 million in total benefits during their child's lifetime. Upon acceptance into the program, NICA has an orientation meeting or conference call with parents, provides each family with a Benefit Handbook (via certified mail), and a letter in which they are reminded of the benefits, which we strongly urge they familiarize themselves with so they fully understand what they are entitled to through the program. NICA case managers, nurses, and administrators are all available to answer questions and assist with navigating the claims process.

Claim: NICA is "flush with cash."

The Truth: Independent actuaries calculate that NICA must commit \$1.05 billion to pay for the expenses of existing children in the program over the remainder of their lives. The NICA Fund currently manages \$1.48 billion, which is largely due to the recent strong performance of the U.S. stock market. However, similar to any other investment fund, investment income for the NICA fund will fluctuate each year and is largely dependent on overarching economic/market performance.

Claim: NICA has paid lawyers almost double what they paid in medical benefits, sometimes spending tens of thousands more on legal fees to fight requests for aid than it would cost to provide them.

The Truth: NICA has paid for parental benefits worth more than 14 times what it paid in legal fees. In total, NICA has paid \$16,979,570 in defense attorney fees/costs since the program's inception. Over the same time, NICA paid \$244,345,466 for parental expenses, including physicians and hospitals, therapy, nursing care, equipment and supplies, and initial awards (\$100,000 one-time award).

Claim: NICA has long-resisted efforts to include a parent advocate on the board of directors.

The Truth: Only one time in the past NICA respectfully offered that there may be a potential conflict of interest. NICA agrees with the Chief Financial Officer's recommendation to include a parent and a consumer advocate representative on the board.

Claim: If families push back, the program sometimes spends more money fighting them than it would have cost to provide help.

The Truth: NICA has not litigated a benefit issue since 2013. NICA works to find an alternative, if possible, that is often more expensive than original requests.