Many of us parents agree that Sue Stuyvesant, in person and with this essay, eloquently described the depth of commitment and frustration that comes from raising a child with special healthcare needs. Her advocacy efforts on behalf of her daughter Michelle were cut short in October 2003 by cancer. Sue's work and the work of families is not done. Too little has changed since 1996; the proposed cuts to the 2004 health budget will gravely worsen the situation. During the budget review for "waste and fraud," please remember where the families of children with special healthcare needs are and what they are doing.

WHERE ARE THE PARENTS?

by Sue Stuyvesant
October 15, 1996

To make a long story short, earlier this week a question was asked by some nit wit official as to why there weren't more parents (of special needs kids) involved in the local PTA and other issues that have come up that directly involve our kids. His question, which was passed on to me was, "Where are the parents?" I went home that night, started thinking – and boy was I pi**ed – and banged this "little" essay out the next day on my lunch break. My friends thought I should share it all with you, and I apologize for the length, but I wanted you to have it all. By the way, I took copies of this to the school board meeting that night, gave it to a couple of influential people and it WILL get around…

Where are the parents?

They are on the phone to doctors and hospitals and fighting with insurance companies, wading through the red tape in order that their child's medical needs can be properly addressed. They are buried under a mountain of paperwork and medical bills, trying to make sense of a system that seems designed to confuse and intimidate all but the very savvy.

Where are the parents?

They are at home, diapering their 15 year old son, or trying to lift their 100 lb. Daughter onto the toilet. They are spending an hour at each meal to feed a child who cannot chew, or laboriously and carefully feeding their child through a g-tube. They are administering medications, changing catheters and switching oxygen tanks.

Where are the parents?

They are sitting, bleary eyed and exhausted, in hospital emergency rooms, waiting for test results to come back and wondering: is this the time when my child doesn't pull through? They are sitting patiently, in hospital rooms as their child recovers from yet another surgery to lengthen hamstrings or straighten backs or repair a faulty internal organ. They are waiting in long lines in county clinics because no insurance company will touch their child.

Where are the parents?

They are sleeping in shifts because their child won't sleep more than 2 or 3 hours a night, and must constantly be watched, lest he do himself, or another member of the family, harm. They are sitting at home with their child because family and friends are either too intimidated or too unwilling to help with child care and the state agencies that are designed to help are suffering cutbacks of their own.

Where are the parents?

They are trying to spend time with their non-disabled children, as they try to make up for the extra time and effort that is critical to keeping their disabled child alive. They are struggling to keep a marriage together, because adversity does not always bring you closer. They are working 2 and sometimes 3 jobs in order to keep up with the extra expenses. And sometimes they are a single parent struggling to do it all by themselves.

Where are the parents?

They are trying to survive in a society that pays lip service to helping those in need, as long as it doesn't cost them anything. They are trying to patch their broken dreams together so that they might have some sort of normal life for their children and their families.

They are busy, trying to survive.