

Special Needs, Part 1



Just before 6 am, a nurse burst into my hospital room, jolting me awake. “You have to come now!” No explanation—just urgency. Still in my hospital gown, I swung my feet over the edge of the bed and followed her into the brightly-lit hallway. She bypassed the elevator, threw open a heavy door and darted down a staircase. I followed, my anxiety rising with every hurried step.

A few flights down, outside the door to the NICU, she finally explained: my newborn son—born the day before at 29 weeks and weighing 2 lb 15 oz.—had stopped breathing and was hemorrhaging internally. The doctors were fighting to save him.

Inside, several physicians were huddled around his incubator. One held my tiny son in his hands, cycling between CPR with a little plastic mask clasped over his tiny face and suctioning blood from his mouth. The nurse and I clung to one another and prayed—silently, urgently. I was utterly powerless, yet grounded by faith in a God that hears and answers prayers. I was not alone.

By 8 am, my tiny son was stabilized but in critical condition. He needed a special ventilator available only at *Primary Children’s Hospital* to keep his fragile lungs from collapsing. While we waited for life-flight, we named him Andrew Elisha—a name we hadn’t previously considered but later learned means, “Courage, God is my Salvation.”

By noon a somber doctor delivered the prognosis: Andrew had hemorrhaged in his stomach, lungs, and brain. The brain bleed was severe. He might never walk or talk. “You may want to consider withdrawing care,” he suggested gently. The words felt unreal.

But my husband and I pressed forward, trusting God and choosing hope. The months that followed were full of oxygen monitors, feeding tubes, sleepless nights, delayed milestones—and beautiful smiles and laughs of a little boy that could melt your heart!

Andrew refused to be left out of the fun with his five older siblings. Before he could even walk, he taught his tiny fingers to shoot rubber bands across the room with uncanny accuracy—a glimpse of the determination that has defined his life.

As he approached age five, a new concern emerged. When I tried to teach him letters and numbers, he couldn’t remember the names of abstract concepts. Colors, numbers, letters—all a mystery to him. He could tell me the white keys on our piano were the color of the snow, but he couldn’t recall the word *white*. I had taught all my older children to be avid readers and learners, but this challenge was new territory.

I dug in. Thankfully, we found a private organization in Utah specializing in brain development. To afford the \$300/month cost, I gave up my cell phone and reshaped our family budget. Their team evaluated Andrew's abilities holistically—auditory, visual, and kinesthetic input; comprehension; motor and communication output—and built a customized program with developmentally appropriate frequency, intensity, and duration. Then they trained us to implement it.

Every day, multiple times a day, for several years we worked that program. Every 3 months we returned for reevaluations and program adjustments. Slowly, steadily, Andrew progressed. Remarkably, by third grade, the child whom doctors thought might never walk or talk was playing basketball and reading and doing math at grade level.

During those years, I often heard the psychologist who helped Andrew lament that, despite robust research affirming the success of their methods, these tools were rarely used in public schools.

Today, Andrew is taller than I am and is serving a service mission for our church. He is a delightful person with a heart of gold. I continue to learn from him daily. Among the lessons learned from my chance to be his mother is this: the right help, given at the right time, can change a life.

Every Idaho kid needs that chance.

There has been concern recently raised—and rightly so—that state funding for special-needs students is inadequate. I share that concern, but our focus must go beyond the bottom line of the budget to how we use those dollars—to serve our special needs students and support the professionals that work with them. In part 2 of this article, I'll share some of what I've learned—and what we can do about it.