A Message from Families:

When a baby is born into a family, there is excitement, expectation and hope. We look at the tiny infant and dream of the future. Who will this baby look like? What talents does she possess? What will he be when he grows up?

When a child has a developmental disability, a whole new range of questions arises. How will this disability affect my child's life? Where will we find information and support? How will we meet our child's needs?

In Maryland, Family Support Services help us find the answers — so that we can raise our children with disabilities at home. We can then see our children not with insurmountable needs, but with hope and promise and all things possible.

— Lee Iacocca

We welcome you to share in the following stories of five different families — families who, with the assistance of Family Support Services, are raising their children with developmental disabilities at home.
Anyone who thinks the work ethic is a thing of the past hasn’t met Carol McMillion.

Ever since her daughter Tracey was born with spina bifida 14 years ago, Carol has been on duty, day and night, seven days a week. As mother, caregiver, manager of transportation and finances, and coordinator of her daughter’s schooling and therapy, Carol has worked tirelessly to assure Tracey’s health and well-being, and has been an unwavering advocate strongly committed to her child’s future.

For Carol, this commitment means dealing with the continual costs and administrative hurdles faced when searching for the medical and therapeutic services her daughter needs almost every day.

Phil, Tracey’s father, is also a wonderful support to his daughter. When not at work, he built a ramp to their Baltimore County home and made the interior more accessible for Tracey’s wheelchair. He has also taken time off, without pay, to be at his daughter’s side during her half dozen major operations.

Tracey’s grandmother was a tremendous source of strength — helping to care for Tracey and providing emotional and financial support to her parents. Her sudden stroke and ensuing death prompted the first call for support from outside the family.

“That year was a low point for us,” remembers Carol. “The expense of Tracey’s medical care was exhausting our already overstrained budget, and I didn’t know where to turn for help.”

Tracey was also facing additional surgery in a few years, which would require home schooling and nursing services.

After several phone calls, Carol learned about the Family Support Services (FSS) program of the Kennedy Krieger Institute, funded by the Developmental Disabilities Administration.

Together, the Family Support Services program and the McMillions identified and coordinated services that would best meet the McMillion’s needs. FSS helped them advocate for educational changes that would challenge Tracey academically. When faced with paying for expensive rehabilitative equipment, the FSS program directed them toward a source for financial assistance. The program also helped the McMillions pay for repairs to Tracey’s wheelchair, building materials for her ramp, and other exceptional costs related to her disability.

Carol and Phil’s wishes for Tracey are not hard to understand. They are what all good parents wish — for their daughter to be happy, to have friends, to develop her unique talents, to provide for herself to the fullest extent possible. They will do anything to make these wishes come true — and the Family Support Services program is there to help.

“You do everything you can and more and sometimes that’s just not enough,” says Carol. “Without the Family Support Services program we wouldn’t be able to meet our family’s needs and we might even lose our child. But now I think we’ll make it.”
Families want and deserve typical, everyday lives.

Family Support Services help make this possible.
On the wall of Kevin and Sondra Smith's townhome, at the U.S. Army's Aberdeen Proving Ground, is a photograph of two bright and smiling little boys, Kristopher and his older brother Kevin.

"Kristopher was born a beautiful, healthy baby who reached all his milestones way ahead of schedule," Sondra remembers. "Then, around 14 months, he started falling and becoming unsteady on his feet." So began an agonizing journey that would have Kristopher and his mother seeing many doctors, and undergoing dozens of tests until the correct diagnosis was made — a neuroblastoma in the adrenal gland, a childhood cancer that affects the nervous system.

"There I was before this happened, with no concept of illness or disabilities, having a great time with my wonderful family," says Sondra. "Then Kristopher got sicker and sicker. One tumor was removed — then another. At that point he was a scared and very sick little boy," remembers Sondra, "but he was still Kristopher." Then, after the first course of chemotherapy, Kristopher caught meningitis and was never the same. He was in the hospital when a doctor told the Smiths that he would never get better, that they should put him in an institution. "We said 'no' and took our boy home," recalls Sondra.

The following months were tough even though the family lived with Kevin's parents, and had a nurse visit every day. Kristopher required oxygen and a monitor for apnea. He had to be fed through a G-tube, needed to be sedated before he could sleep, and had 5-10 seizures a day.

"That's when I first started looking for help of any kind," explains Sondra. "I spent many days on the phone and finally got in touch with the Baltimore County Infants and Toddlers Program. They sent an occupational therapist, a physical therapist and even helped us work with the insurance company."

The Smiths eventually moved to Harford County and contacted The Arc of Harford County Family Support Services program. "I can't tell you how helpful Family Support Services have been," says Sondra. "Until I found them, I remember feeling like I was in this little box, and everything I got I had to dig for. I had to make 10 calls to find one person who could possibly help me." The Family Support Services program helped the Smiths navigate a system of services that is often complex and confusing.

Kristopher has made much progress, but his unique medical and therapeutic needs —
special food, medicine, equipment and care — continue to take their financial and emotional toll on the family. "Our insurance doesn't pay for some things," says Sondra. "We've gone through little Kevin's college account and our regular savings account. My husband makes fairly good money, but we're just getting by."

"Family Support Services did the impossible," Sondra proclaims. "They put us in contact with high school students who were interested in providing care for Kristopher and helped us find the funding to pay for it. That way we could spend some time with Kevin. Things are definitely better for us. And I know they are better for Kristopher too."
Andra Sharp doesn’t remember how many times, in her son’s first months of life, doctors told her that Tavon wouldn’t live. Many, many times she guesses.

“Even when I was six months pregnant, his bladder failed,” she recalls. “When he was born, my family and the doctors said he wasn’t going to make it through the day. He was on a respirator and the urologist operated on him the next morning. I didn’t see him for three days, but when I finally did I decided I would make the best life for him.”

After 17 months of hospitalization for renal and pulmonary failure and then rehabilitation, Tavon came home. Andra and Tavon moved in with her parents because she had been laid off from her job and lost her apartment. She had much to do before her son was discharged, making sure he would have a respirator, the medicine he needed, and nursing care 16 hours a day so she could care for him at home.

“It was an awful time,” Andra admits. “My friends walked away. Tavon’s father wanted no part of his boy’s life. Even my father couldn’t take it and left the house. They all said Tavon would never be okay.”

Fortunately, Andra found an advocate in the Coordinating Center for Home and Community Care (CCHCC), an organization that manages care for families whose children have complex medical needs. They helped her find and pay for an occupational therapist and nursing care, and locate her own apartment in Baltimore. CCHCC also referred her to the Family Support Services program at Kennedy Krieger Institute.

When her second son, Shawn, was born, the Kennedy Krieger Family Support Services program helped her find a bigger place to live. They also helped her pay for tuition and bus fare to attend nursing assistant classes so she could find a job to support her family. As Tavon grew up his needs changed. FSS continued to help by finding summer camp and medical care.

“I always paid what I could,” affirms Andra. “I was brought up to be independent. But occasionally I need Family Support Services to help with necessities and care for Tavon — things we need just to get by and stay together.”

Today, Andra’s family also includes her two nieces. She and all four children live in a nice,
bright townhome on a quiet street in Baltimore. Tavon, now 14, attends regular middle school and takes classes for children with learning disabilities. "Everyone's doing well," Andra proudly reports.
Frederick, Maryland is a long way from war-torn Cambodia where David Bedel, then 10, was hurriedly placed on a boat by his parents, never to see them again. David was adopted by a Frederick family who cared for him but had no way of understanding the trauma or loss experienced by their new son.

Frederick is also a long way from rural Missouri where Tammy Bedel grew up. After Tammy moved to Frederick, she and David met and married and started a family — a family that now includes Britanny, Kathleen, Heather and Abby who has a hearing loss and delayed motor skills.

The Bedels soon began to face many challenges and — feeling like a family in crisis — called the Family Support Services program of The Arc of Frederick County.

David and Tammy knew they could turn to the FSS program for advice and assistance in finding a place to live, medical care and other services — services that would be essential in keeping their family together. This was especially important because David’s adoptive family members were scattered about and unable to offer support.

The Family Support Services program helped David find federal assistance for a disability he has had since birth, and counseling to deal with the emotional scars of his childhood. It helped Tammy apply for medical assistance for the children and get speech therapy and a hearing aid for Abby. Now Abby is attending regular kindergarten with individualized supports. FSS also provided respite care, referral for parenting assistance, and other intensive services.

Through the FSS program, the Bedels found a support group for married couples dealing with disability issues. “We met so many friends there,” says Tammy. “I don’t know what we would have done without it or without the Family Support Services program.” Today, Tammy and David continue to take a leadership role in the support group.

Family Support Services also connected the Bedels with a county agency that led them to a program designed to provide affordable housing opportunities to lower income families. David and Tammy will soon have a new home for their family — in a safer neighborhood, far from the drug traffic and crime outside their small apartment. It is a home they will eventually own with sweat equity and the excellent credit history they worked so hard to establish.

“I just want my kids to be happy and to have lots of friends,” adds Tammy. “And I want them to have a better place to live.” These are wishes that are becoming a reality, through the assistance of the Family Support Services program, and the Bedel’s hard work and perseverance.
Family Support

Services are effective and help families stay together. Families are worth the investment.
At first glance, it could be the room of any two-year-old boy, lovingly decorated by his parents with a baseball glove, a ball, and a varied assortment of sports figures.

Then your eyes turn to the desk, table and play area where Michael, the youngest child and only son of Mike and Patty Roscoe, takes part in a daily home-based instructional program for children with autism or Pervasive Developmental Disorder (PDD).

“We first suspected something when Michael was about 15 months,” remembers Patty, pausing to get her daughter Megan a drink. “A few months later, we got the tentative diagnosis of PDD. That’s when we knew we had to do something.”

The very next day the Roscoes jumped on the Internet and used the library at nearby St. Mary’s College to learn all they could about Michael’s disability. They joined Families for Intensive Autism Treatment and the Autism Society of America — organizations that gave them excellent information and support. Then they looked into the Family Support Services program of The Arc of Southern Maryland.

“The Family Support Services program has been wonderful,” says Patty. “They directed us to a parent support group and the local Infants and Toddlers Program, and even went with me to meetings at Michael’s school to help develop an effective educational program for him.”

With the help of Family Support Services, the couple enrolled Michael in the nearest St. Mary’s County special education program for very young children. But the Roscoes felt strongly that he needed something more — something that would increase the chance that their son could later be mainstreamed in kindergarten and start the journey to a fuller, more promising future.

After months of intensive preparation and with ongoing support from their family and the Family Support Services program, Patty and Mike sought and won approval to begin Michael’s home-based program. As part of the program, they arranged for student teachers from St. Mary’s College to provide daily instruction. It was not easy, but they did their “homework” and were able to get financial assistance for Michael’s educational program.

“We do everything possible to maintain a normal, caring home for our other children,” Patty adds. “But children with PDD and autism require
so much time and personal attention." Patty stopped working after it became apparent that Michael needed extra care, and the strains on both the family's budget and emotions have been enormous. Still she strongly believes it is worth the sacrifice. "If Michael can get through school and make a living in some kind of job with some degree of independence, think of what that would save the State of Maryland," she adds. "We want to do everything possible to make that happen. He's our son."
The stories you have just read illustrate how Family Support Services are an effective, affordable and responsible investment in families. They help families stay together and raise their children with disabilities at home. However, there are not enough Family Support Services to meet the essential needs of families who have children with disabilities.

Even though Maryland is moving toward greater recognition of the needs of children with disabilities, the principle state agency for services to people with developmental disabilities — the Developmental Disabilities Administration — is not adequately funded for Family Support Services. In fact, less than 1% of DDA’s budget is allocated to FSS.

WHAT YOU CAN DO TO HELP FAMILIES:

If you are a Legislator or Policymaker:

- Expand and fund a full range of DDA Family Support Services in every county throughout Maryland to meet eligible families’ needs.
- Assure that Family Support Services receives an equitable allocation within DDA’s budget.

If you are a Family with a child with a developmental disability or someone who is interested in the needs of families:

- Tell your story and that of other families to your legislators so they will better understand the needs of families and how Family Support Services help.
- Let your needs, and the needs of other families who are raising children with disabilities, be known to DDA. Although there are currently not enough services to meet most families’ needs, only by letting your needs be known — and how Family Support Services can help — will this change.

Developmental Disabilities Administration

Central Maryland: (410) 363-2800
Southern Maryland: (301) 317-0325
Western Maryland: (301) 791-4670
Eastern Shore: (410) 219-2828

If you need additional help or have questions, contact the Maryland Developmental Disabilities Council:

(410) 333-3688 or Toll Free: (800) 305-6441
MD Relay: (800) 735-2258