

SUPPORTING *Families* IN TENNESSEE

A SPECIAL REPORT ON THE FAMILY SUPPORT PROGRAM
FOR PERSONS WITH DISABILITIES AND THEIR FAMILIES

SUPPORTING *Fa*



Families IN TENNESSEE

FAMILY SUPPORT IS A PROGRAM ADMINISTERED BY THE DIVISION OF MENTAL RETARDATION SERVICES AND FUNDED BY STATE DOLLARS. IT IS DESIGNED TO HELP INDIVIDUALS WITH DEVELOPMENTAL AND SEVERE DISABILITIES AND THEIR FAMILIES REMAIN TOGETHER IN THEIR HOMES AND COMMUNITIES. THE FAMILY SUPPORT PROGRAM IS AVAILABLE TO INDIVIDUALS REGARDLESS OF THEIR DISABILITY DIAGNOSIS OR AGE.

Daniel Rich's gorgeous smile and generous, outgoing personality light up any room he happens to be in. His overwhelmingly positive attitude belies the serious physical and medical challenges he's had to overcome since being born three months prematurely at Vanderbilt Medical Center. Daniel was able to come home 51 days after his birth on Thanksgiving Day, 2000, but a grade three brain bleed and other complications have resulted in a primary diagnosis of cerebral palsy, and, "a little bit of everything!" as Tracey, his mom, puts it.

It's been an uphill battle for his family to get by financially, providing Daniel with his required medical needs and adaptive equipment and therapies, and emotionally, simply navigating the health care and social service system. Fortunately, this family from Dickson has been able to tap into the State's Family Support program, which has helped them fill in the gaps left by insurance and other funding sources. "Family Support means a great deal to our family," says Tracey. "My husband, Bobby, is the only one who's able to work, because I have to take care of Daniel full time. Although it's not very much, it helps a lot—with diapers, and medicines that aren't covered, gas back and forth to the doctors. Every little bit helps."

What is *Family* Support?

Family Support refers to funding and services provided to help keep a family member with a disability at home, or, in other words, to prevent a person from being placed outside his or her community. Providing supports for persons with disabilities in their homes and communities helps maintain their quality of life—ensuring, to the greatest extent possible, their independence, productivity and integration into the community—and, in most cases, costs less than having individuals in institutions, such as nursing homes and developmental centers for persons with mental retardation.

Flexible, *easy* and family driven

The Family Support program is unique in many ways. Unlike many other programs and services for families and persons with disabilities, Family Support is truly family driven, in the sense that each family, with assistance from Family Support Coordinators, leads the decision-making process concerning the type of support they need to receive. Compared to other programs, Family Support is easy to use, purposely created to not overwhelm families with excessive paperwork or levels of bureaucracy.

Family Support is designed to be flexible too, and highly individualized. Families can choose the services and supports based on their needs and personal preferences, instead of being handed services in a "one size fits all" model. And, most importantly, as a family's needs change, the program can change with them.



Different needs for *different* circumstances

Six years ago, while preparing to snow ski with her son in Colorado, Susan Ritzhaupt was a passenger in a car that skidded off the highway. She awoke in a hospital to discover, gradually, that she had a C4 spinal cord injury, and was paralyzed from the shoulders down. The accident interrupted her career as a teacher of management skills to adults and a Senior Center director, and ultimately cost her her marriage. It took away her independence, and created a situation where her parents, in their mid-seventies, moved from Ohio to become her primary caregivers. "This is something you don't expect to happen," says Susan. "You don't expect something catastrophic. You go about your life, get into your car and run 10 errands in one day."

Susan is grateful that family and friends were there for her, and to help turn her tri-level house in Chattanooga into a more accessible home. Living in her own house allows her to have some sense of continuity with her pre-accident existence. "I think it's just so important for people to continue to have as normal a living situation as possible," says Susan.

In a perfect world, with limitless resources, Susan would like to relieve her aging parents of their caretaking responsibilities, so they can have a more normal life with the friendships they left behind in Ohio. Back in her real world, Susan is pleased to be able to take advantage of the limited funds from the Family Support program, after waiting for two years. "I'm so thankful we do have what we have, and that the program is so flexible," says Susan. "We can use it for respite care, or for a large medical bill. My needs are going to be so different than somebody else who has very different circumstances. They might not need total care, and I always have to have someone with me."

Importance of Respite Care

Although it is just one of many services funded, respite care has been and remains the most requested and needed service for families. In order to maintain healthy family functioning and allow all members of the family to stay together in the home setting, caregivers need time away from their responsibilities. That respite, or break, may be for something as simple as going for a walk or seeing a movie, or to keep an important doctor's appointment.

The demands on families raising children are enormous. In many cases, those demands increase considerably with a child with a disability. Add to that the fact that the divorce rate among families which include a person with a disability is nearly twice as high as the general population, increasing the chance that the individual's primary caregiver will be a single parent.

"You feel like you're in this alone"

In the last three years, Patricia Street and her husband separated, and then Pat contracted two major illnesses. These events added new complications to Pat's life in Nashville with her 15-year-old daughter, Kelsey Scott, who has Down syndrome, and needs

someone with her all the time. Pat has been able to work from home, but during her times of illness she had very limited income. "The first thing that strikes you is you are kind of in this alone," says Pat. "It was a tremendous relief to me to find out there was some help available. I feel like as a society we give a lot of lip service as to a sense of community, but when you do have a child born with a disability, you learn very quickly you are alone, and the responsibility falls on you. There is a really high divorce rate among families where there is a child with a disability. I think a major part of it is the stress—it's a full-time commitment."

It's a commitment that Pat is willing to make for the sake of her daughter, and to continue to keep Kelsey in the family home. "I believe we are a stronger community if nobody's left behind," says Pat. "If people could see some of the struggle, if there was more awareness, I think they would say yes, we want to help. I think there's probably more need than anyone is aware of, and that there are people on the waiting list who are really struggling, and even others who aren't on the waiting list yet, because they don't even know this support is available."



History of *Family* Support



FAMILY SUPPORT WAS ESTABLISHED IN 1988 BY THE DIVISION OF MENTAL RETARDATION SERVICES (DMRS), WITH A SMALL ALLOCATION OF \$108,000, PRIMARILY TO PROVIDE RESPITE CARE FOR FAMILIES. THE PROGRAM WAS INITIALLY ADMINISTERED BY THE DMRS REGIONAL OFFICES THROUGHOUT THE STATE. FOUR YEARS LATER, LEGISLATION WAS PASSED FOR FAMILY SUPPORT AND A STATEWIDE FAMILY SUPPORT COUNCIL WAS CREATED. THE FOLLOWING YEAR, THE COUNCIL DEVELOPED GUIDELINES AND A PROPOSAL FOR CONTRACTING WITH LOCAL COMMUNITY AGENCIES FOR THE DISTRIBUTION OF FAMILY SUPPORT FUNDS.

Local, District and *State* Councils

Family Support was founded on the premise that families are often the greatest resource to persons with severe disabilities, and that a small amount of support is often all it takes to keep families together. That family-centered philosophy also corresponds to the program's reliance on persons with disabilities and family members as key decision-makers on the local, district and State Family Support Councils.

At the State level, the Family Support Council collaborates with the Division of Mental Retardation Services in the development of program policies and procedures. The District and Local Family Support Councils advise and provide oversight for the 20 Family Support provider agencies, and report back to the State Council with recommendations concerning policy, funding and service needs in their area.

Today, there exists one Statewide Family Support Council, nine District Councils and 25 Local Councils. Each entity has different tasks and oversight responsibilities, and an essential element of Family Support is family and consumer involvement. Local Councils were created and meet on a regular basis to provide oversight of the operation of Family Support services within the contract area of the provider agency.

Although the allotment is limited, the Family Support program makes the most of its money. It is a program requirement that 85% of the monies granted to local agencies must go to direct services for families.

More *waiting* than being served

In fiscal year 2004-2005, the program distributed \$7.6 million in State funds administered by 20 agencies across the State. The success of the program is evident, with over 4030 families currently being served, and with an average cost per family served of \$1606 a year. Each county in the State gets its own allocation of Family Support funds, equitably based on its share of the State's population.

In many cases the assistance provided, though small, allows a family to keep their relative at home and avoid undesirable out of home placements. Unfortunately, limited funding for the program also means that nearly 5,100 families are on the waiting list for Family Support—representing 1,368 families from West, 2,194 from Middle, and 1,512 from East, Tennessee. The total number is three times higher than it was ten years ago.

Robin Phillips, Director of Family Support for TEAM Evaluation in Chattanooga, has 250 Family Support recipients with whom she communicates in some fashion on a monthly basis. In a typical three-month period, she handles nearly 800 intake calls. "A constant ringing phone throughout the day, of people checking in about their existing needs, or people with new needs, or other healthcare or State agencies referring people to our program," Robin says. "They know that there's a waiting list, and the quicker they get their folks on the waiting list, hopefully the quicker we can get them additional resources and funding for what they're needing at that time."

One *Family's* Struggle

The Arringtons, from Cleveland, are a large family with six children—three boys and three girls—aged one to ten years. Abby is five, right in the middle. "Abby is our sweet joy," says her mom, Regina Arrington. "She was born February 13, 2000. She was born completely normal. In January of 2001, she woke one morning with a really high fever." Following numerous hospital visits and tests and a harrowing episode when she stopped breathing, Abby has a Traumatic Brain Injury, caused by viral encephalitis from an unknown source.

But Regina and her husband Michael are long past worrying about how it happened. Today, they are putting all their energy and resources into trying to help Abby function better, and balancing her extensive daily routine of bathing, dressing, deep-breathing exercises designed to ward off her seizures, cognitive therapies to help her re-learn the basic skills of life, in addition to trying to manage the care and support of the other children in the family.

Hardest of all, the Arringtons, like so many others, can't find adequate funding for their needs, and were on the Family Support waiting list for six months. "It's an underfunded area everywhere—locally, in our district, in our state and federally," says Regina. "Families need support in many areas for specific things that aren't covered by insurance. Nutritional needs, special needs clothing—there are so many ways we've had to improvise or find creative ways to fund or just go without. Realistically, you can't afford everything, and you have to go with the top priority needs, like food, clothing and shelter."

So why choose to have Abby at home, instead of institutionalizing her, as parents would have done years ago? "Parents value their children more if they're given a reason to value them," says Regina. "If they are given the suggestion that their children are not worth valuing, then I believe that's what they'll end up doing. If we warehouse and stockpile our kids away in institutions, what have we learned? That if we're not competent in certain areas, we can also be institutionalized? If we can give the parents the tools, and the opportunities to help their children, they might respond differently."

In the meantime, Regina, Michael and their six children do their best, which usually requires putting their hopes and dreams—their life—on hold. "Each year that goes by is another year that the things we thought would be accomplished, aren't," says Regina. "It's very simple things, like a getaway—a break for the whole family during vacation times. Saving or planning ahead is difficult, and keeps us from moving forward. We just maintain, and we have to be creative, and hope that one day it won't be this difficult."

TYPES OF SERVICES COVERED

Flexibility is one of the greatest aspects of the Family Support program. The funds it provides can be used for a multitude of purposes, and families have the opportunity to design individualized supports that are not typically offered or funded. Services may include, but are not limited to:

- RESPIRE CARE
- DAY CARE/SERVICES
- HOME MODIFICATIONS
- EQUIPMENT/ASSISTIVE TECHNOLOGY
- SUPPLIES
- PERSONAL ASSISTANCE
- TRANSPORTATION
- HOMEMAKER SERVICES
- HOUSING COSTS
- HEALTH-RELATED NEEDS
- NURSING/NURSES AIDE
- COUNSELING
- CAMP
- TRAINING



Hard choices

Delores Cherry is a Family Support Council Member in the Upper Cumberland area. Her Council meets regularly throughout the year on a strictly volunteer basis—to discuss the requests and the amount of dollars allotted to help the individuals and families in her area. "Which is never enough," says Delores. "So we have to determine where to put what, who needs help with the most important things, and what is necessary at the time."

"Some of my clients struggle from week to week, from paycheck to paycheck," says Elaine Broyles, Family Support Coordinator at H.A.T.S. (Habilitation and Training Service), covering Sumner, Robertson and Trousdale counties. "The children suffer, because there is just never enough funding support to go around."

A higher cost later

Jimmie Lawrence from Memphis has seen her grandson Andy, who has autism, make progress. She is thrilled that he is learning to swim, and that he appears to love music so much. "He's a very loving child," says Jimmie. "They say that autistic children do not show any emotion like love, but he's the type that likes to hug and kiss. He also has the most perfect pitch, and can sing any type of song."

She also thinks he could be doing so much more, if resources were available. She is frustrated by the lack of funding that has left her daughter's family on the Family Support waiting list for five years. "You're begging, you're borrowing, you're re-mortgaging or refinancing your home to try to have the money," says Jimmie, "and sometimes you can't do it."

She believes strongly in early intervention, the concept of working hard with children when they are very young and seem to be most open to learning effectively. "If only the government would step in when these children are first diagnosed and see that they get the proper education and intervention, when they can learn the fastest and the easiest," says Jimmie. "We're going to have to pay for it in the end--when they get older, and get to be adults. It's probably going to cost more. If they're more independent and can do things on their own, the government won't have to be involved as much."

Jimmie can't help getting emotional as she surveys a list of therapies that could be helping Andy, but remain out of reach for the family. They've spent out-of-pocket money on books, educational cards, therapy equipment, doctors, ophthalmologists, neurologists, speech pathologists, psychologists, special furniture, special equipment, all kinds of nutrients and a computer. "This is very expensive," says Jimmie. "I've been retired since 1991. The first year that Andy was in training, I spent \$15,000 of my own money. But you can't go on like that year after year after year."

A rewarding job

Despite the constant need for additional resources, Family Support Coordinator Elaine Broyles has seen her share of small successes through the program, and is thankful for a position that allows her to watch families in the Mid-Cumberland region begin to turn things around. "I didn't realize I would get so involved personally with the clients," Elaine says. "You get really attached, and they're like family. We spend time in their homes doing home visits and meeting with them and their families. It's a very rewarding job."

Joyce Sievers, the Family Support Coordinator at Pacesetters, which covers 12 Middle Tennessee counties in the Upper Cumberland region, echoes that sentiment. "You look at a family's situation, and you're aware of what's going on in Tennessee, and you know that there is no immediate answer for them--or the answer is a waiting list somewhere. If you can provide some little bit of something for them for the first time in their life, there is something utterly satisfying about that. You wouldn't change those feelings for anything in the world."

Joyce, the mother of a daughter with a disability who passed away two years ago, knows firsthand what families deal with on a daily basis, and the financial stress of caring for a family member with few resources. "So many of our families are on very limited incomes," says Joyce, "and if they hit a bump in the road, there is really nothing much out there to help them besides Family Support."



Disability can happen at *anytime*

Carroll Caudle and his wife Margaret Ann have been married for 34 years, and reside in Jackson. In 1966, Carroll broke his leg, and during a fairly routine bone setting in the hospital he had a seizure, which resulted in a chronic seizure disorder. Carroll has been on medications to control the seizures since then, but periodically the toxins



from the medications build up in his system and start affecting his cognitive functioning.

"The burden fell on me to support the family, and my husband felt really bad about it, because he thought he was failing in some way," says Margaret Ann. "I was working seven days a week at almost 60 years old. It was taking a toll

on my body. Then we found out about the Family Support program, and I was able to quit my part-time job. I still have my full-time job. Without this program, I don't know what would have happened."

A *chance* to think about something else

Barbara Lloyd lives in Fentress County with her 36-year-old daughter, Barbie. Thanks to the Family Support program, Barbie has a wheelchair ramp, a tray to fit on her wheelchair, and a bathchair. Two years ago, the Lloyd's Family Support allotment helped them move into a different home that's much more accessible. It is also the first time Barbie has had her own bedroom.

Besides those tangible items that make Barbara's life easier—since Barbie requires support with bathing, feeding and dressing—Family Support has given Barbara the opportunity to remove herself from her care giving responsibilities for brief periods of time. She gets five full respite days a year, and 16 respite hours a month. "I get to get away and think about something else besides Barbie," says Barbara. "I'm getting more support mentally and physically. I was going down with it, I can see now. Mentally I couldn't cope with the situation, and physically, I was getting worn out. I can start my days with a smile now."



Selection *and* enrollment

When eligibility for the program has been determined, families are enrolled and selected based on priorities established by the Local and District Family Support Councils. Once approved for services, a Service Plan is completed by the Family Support Coordinator at the local administrative agency, and the family receiving services. However, the Family Support program recognizes that family needs can change quickly, and the Service Plan may be reviewed and revised as often as necessary to make sure it is still a viable document.

ELIGIBILITY

The process for determining eligibility for Family Support funds is simple, and the requirements are more broad and liberal than many other programs. However, the presence of a severe disability is a necessity.

A severe disability:

- Is attributable to a mental or physical impairment
- Is likely to continue indefinitely
- Results in substantial functional limitations in three or more of these major life activities: self-care, receptive and/or expressive language, learning, mobility, self-direction, capacity for independent living, or economic self-sufficiency.

One of the key guiding principles of the Family Support program is that the determination of the presence of a severe disability is based on function, rather than diagnosis. Disability type or label is not the primary issue; it is the impact of the disability on a person's life.

Unconditional *love*

Amber Buchanan is Valerie Jennings's niece's daughter, but Valerie is now her primary caregiver. Amber, who turned 11 this year, has lived with Valerie in her home in Chattanooga ever since she was born. "That's my pride and joy," says Valerie. "She's my little angel, and the kid I never had, and my husband never had. I think God gave her to us for us to take care of her."

Amber has cerebral palsy, a seizure disorder and scoliosis. "Amber can't talk, but we've talked to her ever since we've had her," says Valerie. "She'll smile, and can't speak back, but I know what she's saying! She knows I love her and she loves me. I'll say, 'Mama loves you,' and she just smiles. That tells me that we love each other."



Valerie and her husband were on the waiting list for Family Support services for a while, but she claims she finally got the funding when she needed it most. Those precious dollars went toward fitting a ramp on the family van, and transferring the ramp to a newer van when the other one died. Although they have not used their Family Support allotment for respite care, Valerie understands how important that service is for some families. "I'm thankful that my husband has allowed me to stay at home and take care of Amber, because it is a 24 hour job," says Valerie. "If I was working, I couldn't be here to do things, or I would lose my job, because she requires back and forth to the doctor and different specialists. And it can take between an hour and two hours to get her ready in the morning."

Valerie's love for Amber includes making sure that Amber stays with her. Even her husband says he would continue to take care of Amber, if anything happened to Valerie. They don't envision Amber in a home of any kind, except the one they share as a happy family.

That doesn't mean they don't worry about the future. "As Amber gets older, I'm sure I'm gonna need help with her," says Valerie. "She's getting bigger and heavier. My thing is to find somebody I can trust being around her, and I can feel comfortable leaving and going to my doctor appointment. I want them to be as concerned as I am about her, and that's my biggest fear--to make sure she's treated right."

Service Coordination *and* Information and Referral

Providing quality assistance to families goes beyond providing funds. It often involves helping families obtain access to other programs or services, benefits or specific information about disabilities. This guiding of families through the often complex and frustrating system of disability services also includes those families who are on the waiting list for the Family Support program.

Staying in the *community* at all costs

Richard Gadbury grew up in Michigan. He was a jock in high school and a good enough student athlete to obtain academic and athletic scholarships for college. He was happily married with three children when a swimming accident left him with a spinal cord injury. This sudden and unexpected turn of events cost him his marriage and much of his autonomy. "I knew after my accident that I had two choices: to get bitter, or better about it," recalls Richard. "I decided to get better."

Richard moved to Chattanooga to escape the extreme cold of Michigan. He arrived in Tennessee with no friends, and no health care, and was getting by with volunteer helpers as personal assistants. "It was difficult to be here," Richard says. "I lived in an apartment complex, and was struggling to find different funding agencies."

Luckily, Richard was able to take advantage of one of his social worker's other recommendations: getting hooked up with the Family Support program. Although the limited dollars cannot cover all his needs and he still relies on volunteers to help in several areas, Family Support helps him stay on his own, in his community. "If it wasn't for the way the dollars are used to help us, most of us would end up in some sort of institution," Richard says. "It would cost society--and the State--a lot more money than these dollars which help us have somewhat of a normal life and hopefully be productive in society. With me, I'm not rich enough or poor enough or sick enough or old enough or whatever to qualify for most of the programs. This program is one where I don't fall through the cracks."

High consumer *satisfaction*

Richard Gadbury is far from the only Tennessean thankful for what the Family Support program offers. An annual evaluation process for the program consistently results in stellar reviews by families and individuals who receive Family Support. With nearly 1700 respondents to their annual survey in 2004, 1624 individuals reported the Family Support program made their life easier; only 6 said it did not. That overwhelmingly positive result is indicative of all of the questions asked each year in a comprehensive survey, regarding agency support, choices and outcomes.

Here are some of the survey comments:

"Family Support provides help not available anywhere else! It helps to bridge the gap between need and the ability of the family to provide for their family member."

"This program makes me feel like somebody cares and I am not by myself."

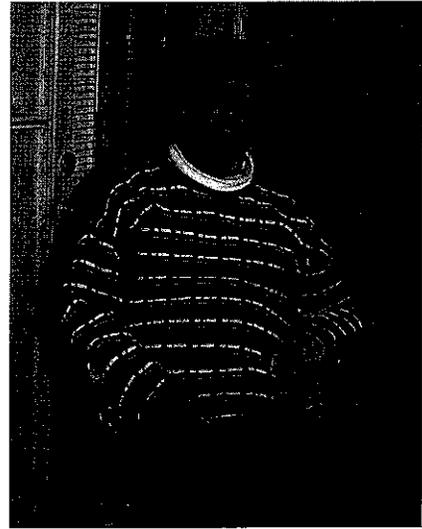
"This program allows my family to spend quality time together. By having respite, my mother and father can get away and not need to worry. It has made a big difference in their life."

"The respite services my autistic son receives allow me to spend some time with my daughter, get dinner cooked and some household chores done. Without this support, I do not think I could deal with the stress of taking care of my son."

"I am a double amputee and you helped me with getting hand controls for my car and a ramp for my front door. My wife and I have no one to depend on but ourselves. Now we can buy groceries and pay bills without having to ask someone to take us."

"Through this program I have received money to pay for respite, home modifications, and a van lift...In addition, the staff have been great in pointing me in the right direction for other services that I might need."

"I really wish they would approve more funding. They just don't realize how helpful it is to be able to choose someone you want to be the caretaker of your loved one. This alone helps you to relax a lot more than having a stranger care for your relatives."



A *Model* Program

The Family Support program in Tennessee has served as a model for countless other initiatives, based on its reputation for being efficient and flexible. One of its best assets is the fact that families can access the program through their local communities, and that many funding decisions are made on a local basis, with oversight from the District and State Councils.

It is also the only program in the State that serves persons with disabilities other than mental retardation, and persons of all ages. For many families, Family Support is the only source of funding that helps the family remain together in their homes, and in their communities. Unfortunately, too few can access the limited funds, compared to the larger number of families that face the difficult challenge of waiting for services.

Appendix

The following is a list of the DMRS Family Support Coordinators for the three Grand Regions and Statewide.

Division of Mental Retardation Services Family Support Coordinators

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"We would like to dedicate this booklet to

the memory of *Susan Ritzhaupt*,
a Family Support recipient who passed away

before its publication."



Tennessee Council on Developmental Disabilities. Authorization Number 339441, August 2005. 3,000 copies. This public document was promulgated at a cost of \$.14 per copy.

A *Special* Thanks

This publication was produced by the Tennessee Council on Developmental Disabilities under the Tennessee Family Support Outreach Project grant from the Administration on Developmental Disabilities, U.S. Department of Health and Human Services.

The Tennessee Council on Developmental Disabilities provides leadership to ensure independence, productivity, integration and inclusion of individuals with disabilities in the community through promotion of systems change.

Photographs by Deana Claiborne of United Cerebral Palsy of Middle Tennessee.

Text by Ned Andrew Solomon, director, Partners in Policymaking™ Leadership Institute/Youth Leadership Forum, Council on Developmental Disabilities.

The Council gratefully acknowledges the support and efforts of the State Family Support Council, Jan Coatney, Coordinator, Family Support Program, and Deana Claiborne in contacting and interviewing the families.

Special thanks to the individuals and family members, Family Support Coordinators and Regional Office Family Support Coordinators who gave their time to be interviewed and contribute their experiences. It's their stories that made this report possible.

