

I Know I Have to Take Care of Myself, But How?

Building a Community Respite Program from the Ground Up

by Martha Toomey

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"So many things we can't control, so many hurts that happen every day, so many heartaches that pierce the soul. So much pain that won't go away. How do we make it better? How do we make it through? What can we do when there's nothing we can do?" How many of us feel this way? We can be kind, we can take care of each other. We can remember that deep down inside we all need the same thing. And maybe we'll find if we're there for each other, together we'll weather whatever tomorrow may bring." Nancy LaMott, 1995

The unfortunate part of living in our beautiful state of Virginia is that we rank 50th in services to families with special needs children. No other state offers less, and the current legislative battles do not indicate any improvement.

There are parts of Virginia that offer remarkable services to families like mine. I just don't happen to live in one of those lucky areas! I was shocked to learn how drastically unprepared my own rural community in Fauquier County was to help my family. I would scream into the wilderness when people correctly suggested I should seek respite. Where? Where would I get respite?

I have a 9-year-old son who has extensive brain damage caused by a vaccination he received when he was

an infant. He suffered from intractable seizures, had brain surgery in August 2001 and a stroke during this surgery. He now benefits from a Vagus Nerve Stimulation implant. My husband and I were handed many jobs, none of which we were prepared for. We now know the insides of hospitals all over the country, emergency rooms, occupational and physical therapy offices, and the special education maze. We're not neurologists but are expected to understand the role of the hippocampus in our son's disorder. We aren't child psychologists but are expected to understand his atypical behavior and know how to live with him. We had to learn how to finesse dentist appointments, haircuts, grocery stores and the car. We planned the day around his seizure activity and often cancelled plans at the last minute. We had three bedrooms so we could take turns sleeping and staying with a sick little boy. Sound familiar?

If you are reading this informative magazine you know the world my husband and I live in. You may be in the waiting room at your child's speech therapist right now. Did you drive through a traffic jam to get to the neurologist this morning? Are you feeling stressed because your child needs to be sedated just to get his teeth cleaned?

Stress is the underlying current that runs through the lives of every parent of a child with special needs. It's easy to get upset when the fights for your child never seems to end. My stress level caused several miscarriages and forced me to have a complete hysterectomy before I was 44 years old. I have a friend who lost her hair, another is dangerously obese. And did you know that 80 percent of parents who have a child with special needs end up divorced? What are you doing today to make sure you are not a victim of your family's stress?

We fight many battles on behalf of our special needs children. Advocates lobby for them, scientists are trying to find cures. If you chose to fight every worthy battle you would be tired, embittered and worthless to your child! This personal frustration compelled my husband and me to start Mary's Family, a respite care program in the Piedmont region for families with special needs children.

Getting Started

In August 2002 I visited the Virginia Disability Commission in Richmond, chaired by Lt. Gov. Tim Kaine. I begged, "What are you going to do for my child?" And the Lt. Governor replied, "What are *you* going to do for your child? And how can the Commission help you do it?" It was a very good question, and one that propelled our community into action. When we thought about what we could do that would make an immediate difference, we quickly came up with an answer: respite.

Our organization offers respite every second Saturday of the month, with a paid pediatric nurse, one volunteer for every child (we include siblings), appropriate activities, and even a 4-H Club. We also help families throughout the month by going to doctor appointments or just by making time for lunch during the workday.

With other parents, grandparents, neighbors and friends, we have successfully held 17 respite days, eight trips and vacations, one camping trip, and even over-night slumber parties! We have worked to ensure that Fauquier County Parks and Recreation knows how to accommodate our children in their programs. We coordinate with Fauquier Citizens for Handicapped Persons, Special Olympics, The Virginia Cooperative Extension office, and the schools. We visit dozens of

groups every month.

What we have started in Fauquier county works, and it could work in your community as well. In order to help yourself, it's sometimes important to ask for help as well. If people know you want respite, and you show them how to offer it (for example, Mary's Family) they will indeed help you. How many people say, "Call if there is anything you need." Well people, when you call your friends and family, give them something practical to do. Show people how to help you!

To begin your own community-based respite program you will need one very important asset: yourself. You are an expert and know first-hand how harsh the world can be. You know other families, therapists and teachers who want to help. Look around your community. Who is in charge?

Strength in Community

We chose to make Mary's Family a "faithful community" because churches are a strong and vital part of our rural community. Mary's Family is hosted by different churches, and our volunteers come from all walks of life, including the schools, community service groups and youth groups.

Your community may be different. You may have a strong city government, a large military base, or an active

labor union. Maybe you live near a state university whose students are required to do community service. There may be groups like the Lions or the Ruritans who are looking for ways to serve. What is your community's strength?

Rely on the unique nature that is your community. We were fortunate to receive seed money to get started. We worked closely with National Organization on Disability, and visited a respite provider in Fairfax County. We created a Board of Directors that helped us get our non-profit status. I am the paid executive director, not a volunteer.

Although you may have family down the street or good neighbors who don't mind helping out, the truth of our lives is much more complicated. Our responsibility as parents of children with differing abilities is quite profound. We need to develop an ongoing community that will exist beyond ourselves. We need to create a safety net for our children's futures. When I ask myself who will be there for my son when my husband and I are gone, I am relieved that we created Mary's Family. This community of people cares for families who have special needs children, including my own. I know there are people in my community who will answer my child's call for

help.

So what did we really create? The greatest gift we can offer someone with disabilities is the gift of friendship. We offer that, but we also offer parents and other caretakers an opportunity to fully participate in all aspects of Fauquier County life. This is respite that works all throughout the month, not just every second Saturday of the month.

Ignore what is supposed to be, the could-have-beens, the why-nots. Concentrate on what is, and what you can do right now. Accomplish something, together, and you will be empowered, and have miraculous energy!

Last year, I received the *Fauquier Times-Democrat's* 2003 Citizen of the Year Award, but although I received the individual recognition, we all know who really got the award. Hundreds of people working together have created a community where there was none, and together we care for one another. If you would like to visit us today, go to www.marysfamily.org. See for yourself what a little relaxation looks like! ■

P.S. The hardest step is the first one. Email me at mjtoomey1995@yahoo.com, and we'll help you find true respite.

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