



The Unique Grief of Special Needs Parents

by Sheri Dacon

The day I found out my boy had autism, I wasn't shocked or upset or wounded. I was relieved.

I was also in denial.

My boy was smart, and I knew that all too well. He was high functioning, and I was confident that we would be able to help him overcome any obstacles before starting kindergarten. By the time he started school, no one would even know. They might just think he was a little quirky. **Plenty of people are quirky. No big deal.**

So I spent that first year with few cares at all, reading a handful of books, learning about social stories and visual schedules and the basics of Asperger's, convinced that we would be past all of it in a couple of years.

Then kindergarten came, and my world got smashed to pieces.

Things didn't work. The new school, the new teacher, everything we had prepared for ... it broke faster than I could scurry around and pick up the pieces. Less than six weeks into the school year, we requested an ARD meeting and moved him to an autism program at a different school. [ARD (Admission, Review, Dismissal) is a meeting where teachers, parents and administrators discuss and create an individual plan for a special needs student.]

We are four years further down the road now. **The social differences are much more noticeable at age nine than they were at five. Instead of getting better, in many ways, the disability has worsened.**

I don't know what it is like to lose a child. It breaks my heart when it happens, because I'm not sure if or how a parent ever recovers from it. **Yet I know brave souls who somehow go**

on after a child's death. I can't imagine what the grief is like.

There is a kind of grieving that exists as well with having a special needs child. My child is very much alive, and I am so grateful, especially since I have witnessed his seizures and considered the possibility, if just for that split second, that he was dying.

But the hopes and dreams I had for my child die a little more each day as I watch him move forward in life. When he was just five or six, I had hope that he would outgrow certain behaviors with age, that he would function better. It was that hope that kept me going. Yet here we are at age nine, and while some behaviors have improved, others have declined.

It is hard to hope when your child pushes against an ever stronger current.

Adolescence is just around the corner and it is scary.

The grieving never ends.

If you let your guard down for even a moment, some terrible incident will come slamming into you, reminding you that your child will never be like the others. He will *always* be different.

Slam.

To accompany the grief, there is its sister – guilt.

Guilt that I did something to cause it. That I should have noticed the signs sooner, gotten more and better treatment, sought a different course or path. That I should be doing more, reading more, helping more, trying harder. That I should spend more time, more money, more effort supporting my child. That I should experiment with a different therapy, a different drug, a different teacher, a different diet. And whenever

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MISSION STATEMENT

FOCUS understands and supports the unique needs of families with children who are medically fragile or have significant developmental or physical disabilities. FOCUS offers comfort, hope and information to parents; accessible recreational and social programs for children and teens; and fun, inclusive activities for the entire family. A nonprofit founded by parents in 1983, FOCUS continues to embrace and strengthen metro Atlanta families.

SUBSCRIPTION INFORMATION

For subscription information, please call FOCUS at (770) 234-9111 or visit our website at www.focus-ga.org. Annual subscriptions to the newsletter are \$15 for families (waived if necessary) and \$30 for professionals.

**From the Editor**

by Lucy Cusick

Merry, merry and happy, happy ... yeah, well, whatever. This holiday season has been less than merry and happy for me. I won't bore you with the list of personal difficulties since we all have our burdens – suffice it to say that I am looking forward to a new year. Some of the struggles will continue, regardless of the change of years, but I am slowly changing my reactions to the struggles. I don't really do New Year's resolutions anymore – but I do use the new year to continue working on the things I should already be doing:

- 1. Exercise.** Yep. I hate it. But, as I get older it takes 'more' to feel the same. Exercise is one of those 'mores.' It might just be walking the dog, but I'm aiming for three long walks and one yoga class a week.
- 2. Eat less.** Of everything, but especially of sugar. It's addicting. One Hershey's kiss leads to a bag, which then makes me want a nap, after which I crave potato chips. It's a delicious and fattening cycle that makes me feel terrible. Especially when standing in front of my closet.
- 3. React less.** My reactions are often my problem. Sometimes no action is necessary – patience might prove valuable ... perhaps someone else will react so I won't have to.
- 4. Drink a Diet Coke a day.** I don't care if it cleans toilets and removes nail polish. I will only drink one, however, and drink water the rest of the time. Well. Except for coffee in the morning and wine on the weekend.
- 5. Plan a vacation.** I didn't plan one in 2013, so guess what? I didn't get one. (Sorry, Camp Hollywood is only a vacation if you have a child attending!) For one week in 2014, you will find beach photos on my Facebook page. Don't worry, none will include me in a bikini. See #2.
- 6. Enjoy more, instead of doing more.** I now make a conscious effort to enjoy whatever I am doing – from standing in line at the grocery store to watching a movie. Don't rush to 'git er done' but enjoy the process. This takes effort for me – and practice. I sure am enjoying assembling this newsletter. Hhmmm.

If I manage to do all of these things, in the same day, I'll be enjoying a day on the beach (#5), taking a long walk after a dawn yoga class (#1), drinking a Diet Coke (#4), but not saving the drowning person (but hoping someone else will) (#3). Yep. Happy New Year! ■

Have you moved or changed email addresses?

Please keep us up-to-date so you receive the most current info from FOCUS!

Find us on Facebook at
<http://tinyurl.com/focusgeorgia>

Speak Out

By Madison DuBois

Some people do not appreciate some of life's little luxuries, while others make a difference in the community. Some people do not realize how lucky they are to have the abilities that they have. When I find myself acting ungrateful, I catch myself because of my volunteer experience.

Today, I am speaking out about an organization called National Charity League, a mother-daughter philanthropy. Honestly, as a younger teenager, I thought it was stupid, but then I grew to realize that we really helped people. I started loving to volunteer when I fell in love with a group called FOCUS.

FOCUS is an organization that reaches out to children with disabilities and their families. It was very scary to me at first. What 14 year old knows how to connect with kids with special needs? The first time I volunteered, I was so nervous. Imagine yourself walking into a room with a bunch of kids you don't know, each of them with a different disability. How would you feel – intimidated or maybe even anxious? I very quickly learned that the kids were so excited to be with a person other than their parent or caregiver. It was honestly such a priceless experience! Their unconditional love and acceptance of me was humbling.

It is crazy how something you did not think would touch your heart can change you, but FOCUS changed me. People say things cannot change you, but, let me tell you, working with these kids, seeing them smile and laugh can make your life change in one single heartbeat and make your heart burst with joy. It was different from anything else I have experienced. I am so happy that I stuck with it.

Charlie (name changed for privacy) made such an impact on me. Charlie has the ability to walk but does not talk. His face, however, would always light up when I came in the room – his face literally looked liked one million cameras flashing at once! Working with Charlie has helped me determine what to pursue in college. I would like to be a nurse so I could make a difference every day to these kids and their families.

We all should look at what we have in life, to realize how lucky we are for what we have. Taking the 'focus' off of ourselves and helping others is one way to do just that! ■

This essay is from a speech that Madison gave to her 11th grade American Lit class about her experiences at FOCUS. Madison and her mom, Monica, began volunteering with FOCUS in 2009, through the National Charity League. Madison is a 'regular' volunteer at Extra Special Saturday respite and Camp Hollywood, and she and her mom (fondly known as 'M&M' by the FOCUS staff) volunteer together at FOCUS on Fashion and the annual Holiday Party. We love hearing how FOCUS – and our wonderful children – change lives!

Seven Things Parents Should Know About Accessible Van Shopping

By Susan Hawkins

As with any product that's been around a while, wheelchair vans have evolved in a number of ways, with a variety of conversion designs and peripheral equipment like wheelchair tie-downs, portable/removable seats, and powered ramps with manual override. Overall, today's accessible vans are more reliable, easier than ever to use, and safer.

If your child's disability requires a wheelchair, and you're in the market for accessible transportation, here are some important guidelines to help you shop:

One Size Doesn't Fit All. A wheelchair van, whether it's transporting an adult or a child, is tailored as much as possible to the physical requirements of the wheelchair user, with family lifestyle and budget taken into consideration as well.

Whether you search for wheelchair vans online or at a local dealership, you'll work with a mobility consultant, whose expertise will guide you through the process, pointing out the technical differences between rear entry access and side entry access, the variety of wheelchair positions inside the cabin, ramp deployment possibilities, and special seating options.

1. The Child's Size. A consultant at a reputable online dealership or local dealership will be incredibly thorough in compiling the details (like wheelchair width and height, your child's height while sitting in the wheelchair, and other essential information), which should help identify the perfect van for your family.

Your child's age and size are factors, too. If your child is a tall, brawny teenager with a permanent sports injury, a rear entry wheelchair accessible minivan should work better because of its wider and higher opening.

2. The Family's Size. Consider the size of your family. A big family (5-7 children) might need the extra room provided by a full-size van. For smaller families, an adapted minivan should work beautifully, and both vehicle styles can be equipped for wheelchair accessibility. Keep in mind that even an only child will have friends who will join you for an occasional outing. With the right seating configuration, a side-entry minivan can transport up to seven (7) passengers (assuming two or three are youngsters).

3. The Child's Condition. Along with wheelchair size, your child's condition has tremendous bearing on vehicle selection. When a child with limited

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Coming Up at FOCUS!

Always check out the calendar at www.focus-ga.org for a complete list of programs!

Let's face it – the FOCUS newsletter is not the best way to find out about upcoming events. By the time you receive this newsletter, Extra Special Saturday respite will have started. You might already have plans for January 25, the annual FOCUS Education Conference. We continue to print and mail the newsletter because parents tell us that they like to throw it in the car to read during therapy, to keep for future reference, or to pass on to grandparents or other parents. So, we'll continue to print, we'll continue to have upcoming events, but if you REALLY want to be 'in the know,' go to the FOCUS Facebook page (<http://tinyurl.com/focusgeorgia>) AND make sure that we have a correct email address for you. We also send weekly emails with upcoming events.

With all that said, coming up at FOCUS:

January 25, 2014

FOCUS Annual Education Conference
at Dunwoody United Methodist Church.

Brochures were mailed to all FOCUS families and you can find the brochure at the FOCUS website.

FAST Fins Registration has begun!

The season begins February 21.
Criteria for swimmers and registration information is on FOCUS website.
Please email Mackenzie@focus-ga.org with questions.

March 15, 2014

"For the Love of Children"
Dinner, Dance, and Silent Auction
honoring Angie and Skip Weiland

Their great love for Bret, their son with special needs, has inspired years of dedicated service to families in similar situations. Angie and Skip left the business world eight years ago to join the staffs of FOCUS and Camp Twin Lakes, partner non-profits that help families with children who have medical or developmental disabilities. Angie and Skip have worked tirelessly and given generously, and we are so proud to honor them.

The Unique Grief of Special Needs Parents

(Continued from page 1)

I try to give myself a break, cut myself some slack from overworking, overthinking, over-trying – **there's always a judgmental comment or stare to put me back in my place.**

Sometimes it brings me to uncontrollable sobbing. I can't make the grief or the guilt go away.

My thirteen year old and I got into a shouting match one day about it. "Why don't you and Dad do anything? **Why don't you make him behave?"** he yelled.

With hot tears washing my mascara away, I argued back, "What would you have me do?!? I've tried everything!! Please, **tell me what to do!!** Tell me! Is there another book to read? Another therapy? Another anti-psychotic drug? I'd love to hear your suggestions!"

Not my finest parenting moment.

And yet if there was one thing I'd want parents of non-special needs kids to know, it's to **please be aware that we – the moms and dads of those "special" kids – are hurting.**

Yes, we love our kids. No, we wouldn't trade them for anything in the world. **But the love we have doesn't take our pain away. In fact, it just intensifies it.** Because we can't take *their hurt* away. We can try and try and try, **and we DO**, and it might even help a little, but we can't make the pain that accompanies disability go away.

When you look at us like we are weird, when you stare and ogle, when you move your kids away from ours, or worse, **NEVER include our child in your child's activities**, it's like rubbing salt into our already raw wounds.

For my son's ninth birthday, we sent printed invitations to school. We invited the entire special needs class, as well as the entire regular class. The invitations indicated that we were serving pizza and that **families were welcome.** We wanted to make sure people showed up. So we bribed them with free food.

Fortunately, all my son's special needs friends came. We have to stick together after all, because special needs kids don't get invited to that many parties.

One boy from the regular class came. One. That's enough to just break a momma's heart right in two.

My anxiety directly correlates to Travis' behavior. When he's doing well, I usually do okay. **When he struggles, I get worse.** I'm sure it could be defined in some complex mathematical formula. All I know is that when he hurts, I hurt more.

And he always hurts.

So next time you are at the Chick-fil-A playground, or at a church picnic, or a Cub Scout campout, try looking at those "weird" kids and their parents a little differently, please? Try to remember that as unlovable as that child might seem to you, the parents are desperately in love with their baby. They are hurting.

And by being a friend instead of a judge or a finger-pointer, you might just make somebody's grieving a little easier. ■

Sheri Dacon has a blog "Lyrics for Life" where she "pours out thoughts on faith, family and struggle." Read more at www.sheridacon.com

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In memory of Rachel Jewel Frey by Janet & Adam Frey
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In honor of John Etheredge's 15th birthday by Keri & Gray Etheredge
In honor of Rebecca Holbrook by Melissa Hunt
In honor of Pete & Pauline Giannakopoulos by Victoria & Lee Livaditis

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Fond Farewells at FOCUS



We at FOCUS are sad (devastated, mournful, grieving) to say good-bye to **Angie Weiland** and **Karen Davis** as they leave FOCUS to spend more time with their families (and to bring us lunch once a week!). They each have worked long and hard at FOCUS – and we are *allowing* them to leave, knowing that we will see them at FOCUS activities (because we know where they live!)

Angie joined the FOCUS staff in April 2006. She's cross-trained in almost every program – from planning the FOCUS Education Conference to organizing (and expanding) FAST Fins Swim Teams to supervising day camp to assisting with overnight camp. Angie often worked 'behind the scenes' and preferred to stay there; at Camp Infinity, she would rather wash dirty laundry than dance to Ice Cream & Cake & Cake in the dining hall! Angie has helped countless parents with questions about everything from Medicaid to respite care. We might forgive her for leaving if she visits and brings us cupcakes!



Karen Davis, nicknamed KD since FOCUS already had a Karen, joined the staff in April 2007. Karen's compassion is immediately apparent when you hear her talking to new parents; her calm reassurance helped so many. She worked tirelessly on FOCUS fund raisers – she can take 10 items of similar colors and make it into a basket that sells for hundreds of dollars in the silent auction!

We will miss her every morning – she always came into the office whistling – and lunch will be quiet without her hilarious tales of life!

Rarely does anyone find an office of women who can all work together without sniping, griping, or crying daily. We get a little testy before a big event, but don't you diss one of our girls – we will circle up and stand together!

The last stanza of *You've Got A Friend in Me* from *Toy Story* says it all – from the remaining FOCUS Girls to our friends who will always be FOCUS Girls, Angie & Karen:

*"As the years go by
Our friendship will never die
You're gonna see it's our destiny
You've Got a Friend in Me."*

New at FOCUS!

"FRIDAYS AT FOCUS" are workshops at the FOCUS office ... on Fridays ... that will begin in early February. Topics include CPR, Social Skills 101, couponing, menus and easy meals, yoga, financial planning, NOW / Comp waivers, deeming waiver, SSI, wills and trusts, insurance, equipment, and more! If you have an idea for "Fridays at FOCUS," please email elizabeth@focus-ga.org. These workshops will be announced by email and will be on the calendar of the FOCUS website.

"TEEN RESPITE" begins in February for teens who cannot attend the Teen & Young Adult events because of their medical condition. Teen Respite will have a nurse, 1:4 care, and really cool activities! For more information, please email Karen@focus-ga.org.

Accessible Van Shopping

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- mobility travels with a ventilator or feeding tube, the vehicle must accommodate it. In such situations, rear entry access is often the better option.
- Side entry vans require the wheelchair user to maneuver into position; an operating ventilator or feeding tube on an independent portable stand can easily make positioning awkward. Rear entry access eliminates the need to maneuver—the wheelchair and ancillary equipment roll directly into position from the back of the van.
- Make sure the above determinants – wheelchair dimensions, your child's specific physical attributes, family size and lifestyle – are addressed by the mobility consultant to zero in on the best-suited van.
- **Seating That Makes Sense.** The van's seating configuration should be based on the condition of your child and how you'd prefer to interact while in the van.
- **4. Seating For a Caretaker.** If you or a caretaker needs to assist him or her, it would be helpful to have a seat right next to the wheelchair, as the front passenger seat can make interaction awkward.
- **5. The Front Passenger Seat.** Now is a good time to talk about the front-passenger seat, which can be adapted for portability, so you can remove it completely. With a wheelchair docking system installed, the coveted front-passenger position is wheelchair-ready.
- That said, size definitely matters here. The laws in some states restrict the size of a child riding in that position, with a typical recommendation of 50 lbs.+ and the ability to tolerate the force of a deployed airbag. A child with a frail or sensitive physical condition should be seated in the middle of the

(Continued on the back)

Looking Back at the Fun ...

FOCUS offers Comfort, Hope, and Fun – and some programs offer them all at the same time! It's comforting to be with other parents who are dealing with similar issues, it's hopeful to see kids who are older and doing so well, and it's fun to be at an event that is affordable and all planned for you!!



**MVP Events:
Boo-B-Que
&
Snacks with Santa**

Holiday Party



Teen & Young Adult Events

Ongoing at FOCUS

MVP Events for Medically Fragile Families

For more information, email elizabeth@focus-ga.org.

Teen/Young Adult Activities for ages 13 to 29

Please email Mackenzie@focus-ga.org for information on monthly social outings and other events for teens/young adults who enjoy socializing but require only a 1:8 ratio and do not need a nurse.

Share Groups, Hospital Visits, and more!

Email lucy@focus-ga.org if you want to get involved at FOCUS but can't figure out how to start!!



FOCUS Day at Zoo Atlanta



FAST Fins Swim Meet

Contributions

(Continued from page 5)

In honor of Golfo & Greg Pappas
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*Thanks to all who placed ads
in the program book and
attended the show!*

Accessible Van Shopping

(Continued from page 6)

- cabin for safety. Make sure to familiarize yourself with your state's seat-belt laws for wheelchair passengers.
- **6. Part of the Fun.** When there are several passengers in the van, middle seating in the cabin would put your child at the center of attention and always part of the fun. The side entry accessible van has an array of configuration possibilities, including jump seats and the potential for passenger seating in front, alongside, and behind the guest of honor in any accessible van.
- **7. Focus on the Future.** As you explore the different wheelchair van conversions, plan for the future. How old is your child, and is he or she still growing? You'll want to prolong the serviceability of this particular investment for many years, with as few – if any – adjustments as possible as your child grows.
- At some point, your child will be eligible to ride in the front-passenger position, so you might want to arrange for a portable/removable front-passenger seat at the time of purchase. Consider the changes that may come over time, and discuss them with your mobility consultant.
- You're now better prepared to choose the ideal wheelchair van for your child and family, with essential features to research and questions to ask your mobility consultant. Go forth and shop! ■
- *Susan Hawkins is a writer and video producer for AMS Vans in Atlanta. This article was found at <http://www.friendshipcircle.org/blog/2013>*

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JANUARY 2014



Sun	Mon	Tue	Wed	Thu	Fri	Sat
			1	2	3	4
5	6	7	8	9	10	11
				Share Group: 9:30am - Gwinnett	Share Group: 10am - Cumming	Respite: 10am - Acworth 10am - Chamblee 10am - Marietta
12	13	14	15	16	17	18
				Share Group: 9:30am - Conyers 9:30am - ExtremeNo	Share Group: 9:30am - Dekalb	Respite: 9:30am - Share 10am - Alpharetta 10am - Grayson
19	20	21	22	23	24	25
			Share Group: 10am - 5 & Under	Share Group: 10am - Marietta		FOCUS Conference
26	27	28	29	30	31	

FEBRUARY 2014



Sun	Mon	Tue	Wed	Thu	Fri	Sat
Visit www.focus-ga.org for the most current information about FOCUS activities.						1
						Respite: 10am - Acworth 10am - Chamblee 10am - Cumming 10am - Marietta
2	3	4	5	6	7	8
MVP Event				Share Group: 9:30am - ExtremeNo	Share Group: 10am - Bereavement	
9	10	11	12	13	14	15
				Share Group: 9:30am - Conyers 9:30am - Gwinnett	Share Group: 10am - Cumming	
16	17	18	19	20	21	22
			Share Group: 10am - 5 & Under	Share Group: 9:30am - Dekalb	Swim: 4pm - Summit Swim 4:30pm - MTV Swim 5:45pm - MTV Swim	Respite: 10am - Alpharetta 10am - Alpharetta 10am - MJCCA Swim 10am - Newnan/Ptre 11am - MJCCA Swim
23	24	25	26	27	28	
N'side Grp 6:30pm Swim: 3:30pm - Cumming 5:30pm - J Creek 5:30pm - Roswell					Swim: 4pm - Summit Swim 4:30pm - MTV Swim 5:45pm - MTV Swim	

Extra Special Saturday Respite – Spring 2014

New registration option for registering your child/children for Extra Special Saturday Respite!! To register your child, email karen@focus-ga.org OR call FOCUS with your child's name and age and the location for which you wish to register. Please note the registration restrictions of each location. If you are registering your child for the first time and would like to talk with someone, indicate that on your message.

Not to insult anyone's intelligence, but here's an example of how to register, using the FOCUS voicemail at 770-234-9111. I would like to register Betty and Jack Smith for respite at Alpharetta Presbyterian on September 21 and November 16 and be on the waiting list for October 19 and December 7. Betty is 5 years old and has cerebral palsy; Jack is 3 years old and has no extra needs. I can be reached at 770-000-0000 if you need to call me about this reservation."

Please bring lunch, extra clothes, diapers, and medication. All medications must be in the prescription bottle, with correct dosage on label. We look forward to sharing an Extra Special Saturday with your child – enjoy your time off!!

Register soon since locations fill up quickly!!

ACWORTH

Summit Baptist Church
4320 Moon Station Lane
Acworth, 30101

*(You may register for three months,
choose wait list for two months)*

**January 11, February 1
March 1, April 12, May 3**

ALPHARETTA

Alpharetta Presbyterian Church
180 Academy Street, Alpharetta, 30004

*(You may register for three months,
choose wait list for two months)*

**January 18, February 22
March 22, April 26, May 17**

CHAMBLEE

Embry Hills United Methodist Church
3304 Henderson Mill Road

Atlanta 30341

*(You may register for three months,
choose wait list for two months)*

**January 11, February 1
March 1, April 5, May 3**

CUMMING

Highlands Church
433 Canton Road, Bldg. 400
Cumming, 30040

(You may register for all dates)
February 1, March 1, May 3

MARIETTA

Mt. Bethel Daycare
615 Woodlawn Drive
Marietta 30068

*(You may register for three months,
choose wait list for two months)*

**January 11, February 1
March 1, April 12, May 3**

NEWNAN

Cornerstone UMC
2956 Sharpsburg-McCullum Road
Newnan 30265

(You may register for all dates)
February 22, March 22, May 17