What I wish I had known (or done differently) when my child was younger

A joint article by The Growing Old Together Share Group

“... We decided to reach out to the “younger parents” with an article for the FOCUS newsletter. What do we wish we had done differently when our children were younger? What are we especially proud of? How could we pass along our “wisdom” in support of parents who are still taking doughnuts to IEP meetings or searching for just the “right” doctor / program / medication? ...”

In September 2019, FOCUS started a new Share Group – the “Growing Old Together” (GOT) group, especially for (ahem) older parents (over 55) of “children” who are over 22 and still living at home.

At our first meeting, we had 16 parents attend! Our introductions are nothing like a “typical” FOCUS Share Group – we are limited to 30 seconds ... 45 under special circumstances! By this time in our lives, the “birth story” doesn’t matter – we need services, help finding those services, ideas for social activities, new non-pediatric doctors, and housing options. We have planned all our lives for our children to be adults – and suddenly they are! But they still require supervision, help with activities of daily living, behavioral and medical support – and more.

So, here we are – Growing Old Together! Our worries are compounded by our own health and mortality. We have always worried about who will care for our young adults when we can’t – suddenly, those worries seem more real. And there are often no good answers. But,
From the Editor…
Self-Care and Holiday Movies
by Frances McBrayer

After reading through the advice from the FOCUS Growing Old Together group in this newsletter, I am more committed than ever to enjoying the little things, celebrating my kiddo as she is, and taking care of myself.

A few weeks ago, I drove to meet my best friend who I have only seen sparingly in the last 20 months of this pandemic. We spent 24 hours together without our kids, and we watched FIVE holiday movies. It was a perfectly low-key time that we both needed, and it was fun!

Enjoying those movies is an act of self-care for me. My family members poke fun at me by giving me Hallmark Channel sweatshirts and telling me that all of the movies have the same plot. But that’s why I like them—I know it will all work out before I sit down to watch! They help me escape my worries and remind me to cherish my family and this holiday season.

I am trying to concentrate more on gratitude for the things that are good about our life right now rather than worrying about the “what happens when” thoughts. Instead of being concerned that my daughter needs specific skills in a specific timeframe, I want to celebrate who she is and what she can do now.

I hope that this holiday season helps us all take the time to celebrate our amazing kids and what they can do. I also thank the GOT group for sharing their wisdom with us and for being vulnerable enough to share their mistakes. We are all better because we have this FOCUS community to teach and encourage us.

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Why We Decided to Vaccinate Our Child Who Has a Rare Disease

Charlie is our five-year-old with MECP2 Duplication Syndrome, a rare neurogenetic disorder. Respiratory infections are often fatal for children with this disorder, so becoming infected with COVID-19 was a major risk for him.

My husband and I have been looking forward to a safe, effective vaccine for Charlie so we can begin to return to a sense of normalcy. Charlie loves interacting with others and enjoys being a part of the world around him. When COVID shut down school, therapy, and the wider community, it was a significant loss.

In thinking about the vaccine as a way to get back to our regular routines and interactions, we consulted with Charlie’s doctors across multiple specialties. They all agreed that getting the vaccine would be the best way to do that for Charlie. He has tolerated vaccines well in the past, so they believed it would be much safer for Charlie to get the vaccine than to get COVID. As an academic researcher myself, I read the data released by Pfizer on safety and adverse reactions. It felt good to know that so few serious side effects occurred in the study.

Parents should make their decisions in consultation with their physicians, but for us, the choice was clear. Charlie has received both vaccine doses without any side effects. He is looking forward to getting back out into the world as much as he did before the pandemic.

By Katie Wester-Neal
in true FOCUS fashion, we do have each other. And we sure have our senses of humor!

After a year of “Zoom Support,” the GOT Group gathered this past October for lunch. We flew through introductions – many of us have known each other for over two decades, some were ‘newbies’ – because we wanted to spend time talking with each other about similar parental issues and discussing some great ideas.

We decided to reach out to the “younger parents” with an article for the FOCUS newsletter. Here we have included some advice that we have compiled as a group, along with some wise reflections from several individuals within the group.

What do we wish we had done differently when our children were younger? What are we especially proud of? How could we pass along our “wisdom” in support of parents who are still taking doughnuts to IEP meetings or searching for just the “right” doctor / program / medication?

So, here goes – we don’t agree on every single point … but take the information as it is given. With hope. With courage. With experience. Topped with a lot of love and understanding.

✔ MORE believing in yourself & your gut. LESS worrying about the future; MORE living in the present!

✔ Have an answer ready for people who say, “I wish there was something I could do for you,” or “How can I help you?”

Can you come to my house and play with ________ for an hour (or more)?

Will you pick up ________ for me from the store?

Hugs, prayers, errands, just come sit with me...

✔ Talk to every parent you can.

✔ Don’t rely on the advice of just one person. Seek out others. And don’t stay with just those with the same diagnoses. All special needs parents offer a new outlook and different perspective.

✔ Ask, ask, ask, ask any question you want to the doctor. Don’t worry – someone has asked it previously!!

✔ Listen to your gut – if you don’t like the doctor/provider, find another one.

✔ Don’t go to a doctor or therapist you wouldn’t invite to your dinner party. If you are not comfortable with them and don’t feel a mutual respect, move on. There are plenty of them.

✔ Self-care IS IMPORTANT. It is a necessity not a luxury. We are better parents when we take care of ourselves.

✔ Self-care. I learned the hard way to take care of myself. At one point I could not move my neck because of carrying my son, due to lack of exercise and stress. From that I spent months in chiropractic care.

✔ I would have taken vacations with my husband, without children, even if just for a weekend.

✔ Exercise when you can – if even just taking walks. Realize you will need to keep getting stronger as your child gets bigger. Remember what they say as they give instruction before you fly in an airplane – “Put on your own oxygen mask first…”

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✔ Exercise when you can – if even just taking walks. Realize you will need to keep getting stronger as your child gets bigger. Remember what they say as they give instruction before you fly in an airplane – “Put on your own oxygen mask first…”
✓ Give yourself time and space when you feel your patience wearing thin. Closing a door between you and your loved one can sometimes be the best way to respond (especially if you are too upset, tired or stressed). It helps to step outside to take a breath.

✓ Get outside as much as possible! From the time the he could walk, my son was an escape artist. He slipped away from us and went inside neighbors’ houses without saying a word! We put deadbolt locks on the outside doors of our home and were fearful every time he was out of sight unless he was asleep. As a result of this, as well as his ABA therapy, speech therapy, and OT, we spent too much time inside. When we did venture out, he would wander if you did not hold his hand and he did not want to be restrained in any way! When I think about those days now, I wish we had found safe places such as a big field or a walking trail where we could let him run and allow him the freedom to explore safely and still allow us to keep up with him. I would encourage OT and speech therapists to work with children outside, swinging or climbing in a natural environment. We have found that physical activity helps my son focus and relieves much of his pent-up energy and anxiety. He now hikes, swims, or bikes every day.

✓ Tell everyone who tries to draw blood: YOU GET ONE STICK! She is not a pin cushion and if you don’t think you can get blood the first time, get someone in here who can!

✓ Yep, one stick is the only chance you get! (Blood draw nightmares).

✓ Never give up any services (PT, OT, ST) in school.

✓ The best skill my son with cerebral palsy has is “stand-pivot.” He can bear weight (with grab bars) to stand from his wheelchair, pivot, and sit in a chair / on a toilet / into bed. Because of this one skill, he is independent for most of his self-care needs.

✓ I would have gotten a wheelchair for my son years sooner than I did. The walker held him back in so many ways, and in the end, he uses a wheelchair full-time.

✓ I would have gotten a wheelchair accessible van and made the bathroom modifications MUCH sooner. I waited too long and injured my back before I got those two necessities done.

✓ We would have paid more attention when the school system politely told us to prepare for transition from school to “real life.” It was incredibly difficult to find a day program for our SID/PID (severe intellectual disability/profound intellectual disability) daughter in Gwinnett County, one of the most populous counties in the nation! There are almost no day programs that can accommodate SID/PID.

✓ I do not know of anything I would have done differently for my son with special needs, but maybe I would have tried to take better care of myself and spent more quality time with my daughter and hubby.

✓ I’m pretty organized with paperwork but I would have been even more diligent with organizing! Would have done more “life” therapy at home when she was very young.

✓ I would have done less therapies. Six a week was too much. Instead, I would have done more playing with the neighborhood kids. More trips to the park. More fun activities. I think my youngest (typical sib) would have enjoyed it more than sitting in waiting rooms. I don’t think all those therapies really made much difference for my son with special needs in the end.

✓ MORE listening to other parents: CHOA Clinic on Alpharetta Highway had a parents’ waiting room where we had weekly discussions and it really helped us a lot, in search of medication, other “innovative therapies,” each families’ perspectives on having a special needs child … (that was 20 plus years ago, at CHOA).

✓ My typical daughter watched swim team practice next to my son’s aquatic therapies. That’s how she learned how to swim just by watching! Could have spent more time with my daughter, but in a way the other child was learning a lesson to maximize her time spent at my son’s therapies, tagging along.

✓ Nothing. Things turned out great for my son who is now 31. He needed more social skills and such when he was in school. Because of that he was able to go to technical school and get his GED going to regular classes with very few adaptations. Granted, he will always have autism, but at least autism doesn’t have him. He currently has his sportsmen and trappers license and will be going into business for himself with his older brother.

✓ Even though it is extremely hard, do not be consumed with your special child. Save time for your other family members.

✓ Keep a journal or a detailed list of the Medical History of your loved one. You will appreciate this greatly as the years pass and you will see when they had their diagnoses, immunizations, procedures, etc. This is a living document that you will add to each time you see a doctor, have appointments or attend special therapies or activities. Just include what you see as important to remember.

The FOCUS GOT Group meets sporadically and is led by Lucy Cusick and Deborah Fields Harris. If you have a young adult with disabilities who still lives at home, please join our Facebook Group “FOCUS GOT Share Group.” We don’t have all the answers, but we have each other – join us as we grow old together!
A Look Back:
FOCUS Family Days at Six Flags, Zoo Atlanta, Atlanta Botanical Gardens and FOCUS + Lekotek Holiday Party
In My Own Words: Teen & Young Adult Activities

By Nicholas Stevens (and his mom Vickie)

“My favorite thing about teen group is dancing, and my friends. The Lovett dance is the best. I am happy when I see my friends.” – Nicholas

“We love FOCUS and all it has to offer for families. From the conference to Six Flags and camp, we feel supported and able to participate in many many things. We love FOCUS!” – Vickie
Preparing for Overnight Camp

By Anna Thielemann

FOCUS has been a part of our lives since moving to Atlanta when Louisa was four years old. Louisa is now 24 and has participated in so many different FOCUS activities through the years.

Since she is now a bit older, she has been lucky to attend some of the overnight camps. Looking back at her T-shirts, it was 2015 when she went to Octoberfest for the first time. This was quite momentous because, at that time, I could not imagine my daughter spending the night anywhere without me. How could either of us survive that?! It was a hard process for me to let her go that first time. The wonderful team at FOCUS and the volunteers were there every step of the way to encourage us.

Since that first overnight, I have put my trust in the team at FOCUS and their volunteers, and we haven’t looked back. Louisa’s experiences of zip lining, performing in talent shows, horseback riding, rock climbing (!!) and whatever else she has done are memories that are her own. Camp pictures decorate her walls, and she names off the friends she has made through the years.

I might not always know everything, but I have learned to let go a bit, to give her the chance to grow and to see how happy she is when she says she wants to go back! Then I know, all is well, and I am so thankful!

Check our calendar at www.focus-ga.org for the most up-to-date information!
A Look Back: FOCUS Camp Octoberfest
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Tanisha Appling & Mokiece Jones
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Sally Bauer
Leonie & Jim Baxter
Beverley Boucaud Taylor
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Joy & James Trotti
Mark & Tracy Turpin
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Angela Weiss & Kevin Kirchner
Susie Williams
Rachel Wittenberg & Asher Vilenks

In Memory of:
Cameron Freeman by Melinda Reed
Nicholas Median by Robert Heitert
Lawton Family by Susan Folger

Steven Winokur, Logan Beasley,
Luke Albano, Noah Anderson
by Belinda Daywalt
Beverly Barach Morick by
Doreen & Burt Wittenberg for
the Liam Vilensky Scholarship Fund

In Honor of:
Jackson Puckett’s Birthday by
Carey Jackson
Jorge Leonardo Perez by
Meghan Burke & Gregory Abowd
Kai & Emmy Rose Jeyaram’s Birthdays by Lynda Lee Moser
Katie Norris by Kathleen & William McNulty
Lucy Cusick by Anita & Scott Tiedt
Lucy Cusick by Rhonda O’Gorman
Lucy Cusick by Chris & Randy Hamilton
Nick Kostopoulos’ Birthday by
Pauline & Pete Giannakopoulos
Angie Weiland’s Birthday by
Marcy & Jerome Konter
Kirk & Scott Lawton by Celia & Frank Lawton

Thank you to all those who participated in the Blue Ridge 250 on October 2, 2021! All riders’ fees were donated directly to FOCUS, and over $18,000 was raised to support our mission! Special thanks to chairmen Ben Cheatwood and Sam Shaw for their continued support of FOCUS and for organizing this great event. We are so grateful!

In Memory of:
Claire Gibbs by Steven Becham
Anne Moroz by Sean Moroz
Howard Lucas by Martha Lucas
Joseph Berry Jr. by Sharon Rivera
Kimberly, Keny, Kiley & Colton by Judy & Ken Hammett
Marion & Martha Trotti by Ann & Randall Coggins
Marion Trotti by Patty Vastakis
Nikolaos S. Vastakis by Georgia Vastakis
Robert Kushner by Ellen & David Herold

Thank you to VOYA for hosting two employee campaigns supporting FOCUS this quarter. We are so appreciative of your donations!

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Huge thanks for those who created Facebook Giving Campaigns for FOCUS!

Carol Sabo Smallman
Megan Gareau’s 10th Birthday Facebook Campaign in Memory of Claire Gibbs

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It was slow at first. New doctors, new terms, new tests … but no answers. We were in limbo. Doctors were very vague and technical. We had no understanding of what our future held.

I’m not sure when we really grasped our long-term expectations, but I do remember meeting people that helped us along the way. One of the first FOCUS conferences we attended introduced various resources for us to reach out to. Little by little, we found other resources that helped Trevor and our entire family. I am grateful for all of the teachers, therapists, camps, parents, volunteers and organizations that have eased the path over our family’s last 20 years.

Looking back, we have been very fortunate. We’ve made great friends and met incredible people. We have also had tremendous resources to help make Trevor’s life wonderful, and our journey as a family something to be proud of.

I am about to embark on a different journey. I am setting off to hike the Appalachian Trail on February 27, 2022. To honor those that have helped us along this journey and to ensure that the resources we have enjoyed are available to as many families as possible, I am dedicating my trek to the special needs community and specifically to FOCUS.

I am so appreciative to everyone that has been on our journey, and I am aware that we’ve had more opportunities than most families. I want to raise awareness of the challenges that families of children with special needs have and work to make sure other families are connected to the resources they need.

We are truly a Special Community, and I hope this effort can make just a little impact for everyone who is on this journey with us.

Join Curt on his Appalachian Trail adventure @ TrekkingforTrevor on Instagram, Facebook group, and YouTube. You can also learn more at https://focus-ga.org/trekkingfortrevor. Please share with your friends!
Save the Date!
FOCUS 35th Annual Education Conference
January 29, 2022

For the Love of Children Gala
February 26, 2022
https://focus-ga.org/gala

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In November, the Dunwoody High School National Art Honors Society Students volunteered their time, effort, and creativity to create a beautiful mural in the lobby of the FOCUS office! These students helped make the office more inviting and friendly for children and families when they visit. Thank you!