



I WANT YOU!

The Family Café CHANGE AGENT NETWORK THEY NEED YOU!

Volume 1, Issue 4

This Newsletter Is A Project Of The Family Cafe

April 2018

The Change Agent Network is a project of The Family Café and offers an opportunity for advocates and change agents to work collaboratively to transform the system by: combining abilities, skills, ideas, and talents; standing together for meaningful system reform measures; taking the lead in our communities and neighborhoods; sharing information to help families become effective players within their communities; developing statewide networks to organize and discuss the issues that are most important to families and persons with disabilities; and creating a united position on critical disability policy issues.

Children’s Mental Health Awareness Week May 7-13, 2018



"Partnering for Health and Hope Following Trauma"

Each year National Children’s Mental Health Awareness Week seeks to raise awareness about the importance of children’s mental health and show that positive mental health is essential to a child’s healthy development from birth.

Join us as we join other states in celebrating Children’s Mental Health Day on Thursday, May 10th.

Join us as we focus on the importance of an integrated approach to caring for the mental health needs of children, youth, and young adults who have experienced trauma, as well as their families.



WWW.FAMILYCAFE.NET

The Whole of Our Family-Run Organization Movement Will Be Greater than Any One Part!

Last year a group of families and advocates came together at a pre-conference training just prior to The Annual Family Café in Orlando to talk about building a strong, unified voice for Florida families and the organizations that represent them. Since then, we have exchanged emails, held conference calls, and met face to face in Orlando, as we have worked to create a Unified Voice of Family-Run Organizations.

What is a Family-Run Organization (FRO)? A FRO is managed and run by family members—those who have lived experience in caring for a child or family member with a disability. And these family members often coach and support other family members who may be experiencing the challenges of navigating a disability—this is called family-to-family Peer Support. Additionally, a Peer-Run Organization (PRO) is managed and run by peers—those who have personal lived experience with a disability. Similar to the family members helping family members, a peer who is providing support to a fellow peer is providing Peer Support.

Now it's time to take the next step, by once again coming together for a pre-conference meeting on the Thursday prior to The Annual Family Café. We invite you to continue the journey by attending **Family-Run Organization Summit: Part Deux!**

This daylong Summit will be held Thursday, June 14th from 10:00 a.m. to 3:30 p.m. at the Hyatt Regency Orlando located at 9801 International Drive in Orlando, Florida. This session will once again be facilitated by John Ferrone, who began this journey with us last year. He is a family member and a national expert in family-run statewide visioning and strategic planning.

We plan to come together to continue the exploration and definition of a collaborative model that will help our Family-Run Organizations better serve Florida's families, youth and children. Our goal is to review the progress we've made this past year, and to identify and pursue the next steps towards creating our Unified Voiced.

Don't miss out on the continuation of our planning initiative!

No registration fee required, so pack a bag and **join us** as we review a **Vision of our Unified Voice**, and discuss how to move towards *contributing to policy formation, service design, and funding allocation at the statewide level.*

Please complete the enclosed registration form and return it to The Family Café by email to info@familycafe.net, fax to 850/224-4674, or mail to 820 East Park Avenue, Suite F-100, Tallahassee, Florida 32301 by Friday, May 18th.

The Whole of our Family-Run Organization Movement...

Family-Run Organization SUMMIT: *Part Deux*

at

The 20th Anniversary Family Café
Thursday, June 14th, 2018
10:00 am – 3:30 pm

Hyatt Regency Orlando
9801 International Drive
Orlando, Florida

No Registration Fee Required!

Sponsored by...



...will be greater than any one part.

The Family-Run Organizations of Florida began a journey one year ago to create a Unified Voice. Join us at the 20th Anniversary Family Café for *Part Deux* of this effort. The daylong Summit will continue the exploration and definition of a collaborative model to be the home of our Unified Voice to better serve Florida's families, youth and children.

We will review a **Vision of our Unified Voice**. We will discuss how to move forward sharing our Unified Voice towards *contributing to policy formation, service design, and funding allocation at the statewide level*.

John Ferrone began this journey with us last year, and he will continue facilitating *Part Deux*. He is a family member and a national expert in family-run strategic planning and statewide visioning. Our goal is to review the progress we've made this past year, and to identify and pursue the next steps towards creating our Unified Voiced. **Don't miss out on the continuation of our planning initiative!**

If you would like to attend, please complete the following form and return it to The Family Café by email to info@familycafe.net, fax to 850/224-4674, or mail to 820 East Park Avenue, Suite F, Tallahassee, FL 32301 by Friday, May 18th.

No Registration Fee!



John Ferrone is a nationally recognized consultant, organizational coach, and family member. He specializes in assisting family-run organizations to build capacity to be sustainable, as well as how to collaborate and achieve a statewide vision. He has presented at the Georgetown Summer Institute, as well as many SAMHSA family conventions.

www.ferroneassociates.com

Name: _____



FLORIDA DEPARTMENT
OF CHILDREN AND FAMILIES
MYFLFAMILIES.COM



Address: _____

City: _____ County: _____ State: _____ Zip: _____

Phone: _____ Email: _____

Organization: _____

Update on the Florida Children's System of Care

By Emily Pritchard, DCF

On November 2017, the Department of Children and Families (DCF) convened a statewide advisory team consisting of family members, youth leaders, representatives from child serving agencies, and other community stakeholders. The mission of this team is to transform Florida's child serving systems, making it easier for youth and families to access needed mental health services and supports.

As a parent of a child with behavioral health challenges, I have found the task of locating and accessing necessary services daunting. Although our family had some fantastic workers and counselors, it often felt like something was missing and that our needs were not quite being met. I felt like no one could really understand what we were going through. So, when I heard about the amazing work being done by DCF to help transform systems to a more family driven, youth guided approach I jumped at the chance to join their team as the statewide Family and Youth Coordinator.

The family driven, youth guided approach recognizes that individuals are the experts on themselves. They need to be empowered to identify their needs and make decisions about what will best help them meet their life goals. Youth and families are included in the system design process so they can give real time feedback about what traditional and non-traditional services will best assist them on their journey to mental wellness.

There are many opportunities for family and youth to get involved in this planning process and have their voice heard. The statewide advisory team has workgroups that are currently identifying goals and strategies to improve the system of care. Each of these groups has family members and/or youth involved, but we can always use additional voices. The workgroups will report back to the statewide advisory team during monthly meetings to shape policy and procedure statewide.

Florida will join other states in celebrating Children's Mental Health Day on May 10th, 2018. This will provide a great opportunity to bring attention to this important issue. A youth advisory board is being convened to help plan campaigns to bring attention to Children's Mental Health across Florida. The Florida Children's System of Care will be engaging in a statewide social media campaign to promote hope following trauma and we hope citizens across Florida will join us in this effort.

The Florida Children's System of Care is also proud to continue to be a part of helping to shape a statewide collaboration of family run organizations. In February 2018, a meeting was held in Orlando to continue the visioning process begun June 2017 at the Family Café Conference. We look forward to continuing this important planning with family run organizations at the next meeting on June 14th, 2018 at the 20th annual Family Café Conference.

If you are interested in having your voice heard and getting involved with system of care efforts at the state level or in your region please contact us at hqw.samh.socflorida@myflfamilies.com. Please also visit our website at www.socflorida.com

WWW.FAMILYCAFE.NET

My Story!!

By Tammy Turner

Growing up I think I was like most girls. I had dreams of my future. I wanted to get married, have babies, and live life on love. I wanted to be a great mom and a perfect wife. I just knew I was going to marry my prince (Tim), and we were going to live happily ever after. Before we were even married I saw some snapshots into the future that should have given me some indication of what just might be in store. My husband-to-be's friends were teasing him that they were going to take him out before our wedding for an evening filled with fun. My husband-to-be was so anxious about what they had planned that he could think of nothing else. We were trying to plan our wedding, and he was panicking over something that did not ever happen.



Our wedding went off without a hitch, and for the first year things went pretty smoothly. We were married three months when I became pregnant with our daughter. I had a lot of all-day sickness, and by the time I was seven months pregnant I began having issues with my blood pressure. The doctor put me on bed rest. The same day, my husband had such a migraine because of the stress of this that my dad had to take him to the hospital to get a shot to stop the migraine.

A few months after our daughter was born my husband had bad chest pains and had to be rushed to the hospital. I was a young mother. My husband was young himself, and the doctor was telling me, "We are sorry Mrs. Turner, but your husband has had a heart attack." He spent 3 + days in the hospital for testing. The cardiologist determined that he didn't have a heart attack, but rather a panic attack. Several incidents followed this one, each requiring at least a three-day hospital stay.



When our daughter was four years old, Tim was working as a department manager for Walmart. He was working many hours each week. One night he was locked in the store with other staff for overnight inventory. Tim had a panic attack so bad that he had a nervous breakdown. He left work that night and never returned. He was referred to a psychiatrist who diagnosed him with panic and anxiety disorder, as well as bipolar disorder. He was put on many medications to try

and manage his anxiety. He became agoraphobic, and for quite some time would not even go out of the house for any reason. If he did go out, to even a small convenience store, his panic would get so bad that he had to leave immediately. Throughout this time he saw a therapist regularly. That therapist told him that he was lucky that I stayed with him, that most marriages affected by mental illness failed.



Fast forward several years. It was the end of our daughter's second grade year. The teacher let the kids who had summer birthdays choose a day during the year to celebrate their birthday. I made cupcakes for our daughter, put them in the oven, and told Tim to take them out when the timer buzzed. I had to take the kids to school. When I came home the house was full of smoke, and Tim was sound asleep on the couch. He was so medicated that he was totally unaware of what was happening. I came in, took the cupcakes out of the oven and started screaming at him. He woke up, sat up on the couch, very confused. I took a plastic cup off the kitchen counter and threw it across the living room. It hit the wall right above his head. I turned back to the mess in the kitchen, and started over, making the cupcakes again. The next thing I heard was a knock on our door. I opened the door to see 2 deputies standing there asking me where the weapons were. Unbeknownst to me Tim had taken the cordless phone into the bathroom and called 9-1-1. His medication made him very paranoid. He was in fear for his life. When the 9-1-1 operator asked if I had any weapons, he told them I was in the kitchen, and there were knives in there. After questioning me for a while, they realized that Tim was mentally ill, and in no danger. Before they left they asked if I was okay.

During that same year Tim was admitted into the local mental health facility several times. Once I found that he was taking a medication that the doctor had taken him off of, I called the doctor to ask what I should do. He said to call 9-1-1. The doctors Baker Acted him for a period of time until he could be stabilized. Another time he took a month's supply of Xanax in nine days. He didn't even realize it. He said he just wanted the anxiety to go away. I took him to the hospital that time. All the way there he kept saying that I just wanted to get rid of him. As a mother of two young children, it definitely wasn't my desire to get rid of their dad and be a single mom. I knew he was sick, and he just needed help. Throughout this time he would have pity parties for himself. He would tell me that he would leave, go live under a bridge. I would tell him to make sure he told me the location of the bridge so that I could bring the kids to visit him.



Life was not all horrible. There were many good times. For periods of times he would participate in the dads' group at school, volunteer in the classroom, take the kids to church, go with the kids to doctor appointments, support our son with his IEP's, and many other good times. We have many good memories, and we try to focus on those. We started attending The Family Cafe' in 1999. We missed the first year because I was participating in the Partners in Policymaking training program. For many years when people saw Tim coming they would turn and walk away. He was just so out of it that people could not deal with him. They didn't want to talk to him. But one year things changed. Tim was tired of living like a miserable zombie, so he went cold turkey off of his medication, without my knowledge, or the doctor's knowledge. We don't recommend this. He began to live life again. He went through substitute teacher training, and became a substitute teacher at our local high school. He took on a volunteer coaching position with the football team. He also became the assistant head usher at our church. Around this time he was diagnosed with celiac disease, which we believe may have contributed to his mental health issues. With his diet change we began to see a huge decrease in his panic and anxiety attacks.

But what really made the biggest change in his life was the year that The Family Cafe' was at serious risk of losing some supporting funds. Tim had a new purpose. He got busy making phone calls and setting up visits. He reached out to fellow advocates to do the same. People listened. People began to look up to Tim as an advocate and a leader. Tim had a message and he learned how to make people listen. Tim has been on the Board of Directors for The Family Cafe' for several years now.

What made me stay with Tim when he was so ill? When things were so hard? Any time I was ready to give up I thought "What if tomorrow is the day things change?" I just knew that I could not give up on him. He has always been an amazing dad and a loving husband. That determination to never give up has resulted in some beautiful fruits. We now have two adult children who still live at home. My daughter is a foster mom, soon to adopt her almost-five-year-old son who has autism. She also has a foster daughter who will turn one in August. Another member of our family is our one-and-a-half year old great niece. It isn't easy starting over raising children in our older years, but we couldn't think of anything we love more. It can be chaotic, and difficult. We are often exhausted. But the payoff is hugs and kisses, giggles and belly laughs.



Mental illness does not have to be a death knell. We know that not everyone with a mental illness can make such a drastic change. But we know that there is hope. Hope that with proper medication and therapy things can change. Hope that with purpose a person can focus on something that is far greater than themselves. That with support a person can live the fullest life they possibly can. No, our life is not perfect. I am far from a perfect mom and wife. But one dream was fulfilled. My family, as chaotic as it can be, lives on love. That is what makes life perfect for us!



Congratulations Ms. Wheelchair Florida 2018, Ms. Shavaugh "Shevie" Barnes!

This year, women from across the state of Florida participated in an empowerment conference where they gained resources and skills in order to become an effective change agent in their respective communities. Ms. Wheelchair Florida 2018 empowerment conference and gala was a huge success, one of which many are still reflecting upon.

There were 9 contestants this year representing Hillsborough County, Duval, Palm Beach County, Orange, and Polk County, to name a few. These women exemplified strength and determination, not allowing any obstacle to hinder them from accomplishing their goals.

Congratulations to our own Florida Youth /council member, **Shavaughn "Shevie" Barnes of Jacksonville, Florida for being crowned Ms. Wheelchair Florida 2018!** We are very excited to be a part of this journey with Ms. Wheelchair Florida 2018, Shevie Barnes, as she represents the beautiful sunshine state of Florida and advocates on behalf of all those with disabilities! We are so proud of you!



Yvonne Milton, 1st Runner Up; Emily Wilson, 2nd Runner Up; Lori Monti, Ms. Congeniality Award.

20

th ANNUAL

Family Café

JUNE 15 - 17, 2018 • ORLANDO

**HYATT REGENCY
ORLANDO**

9801 INTERNATIONAL DRIVE
ORLANDO, FLORIDA



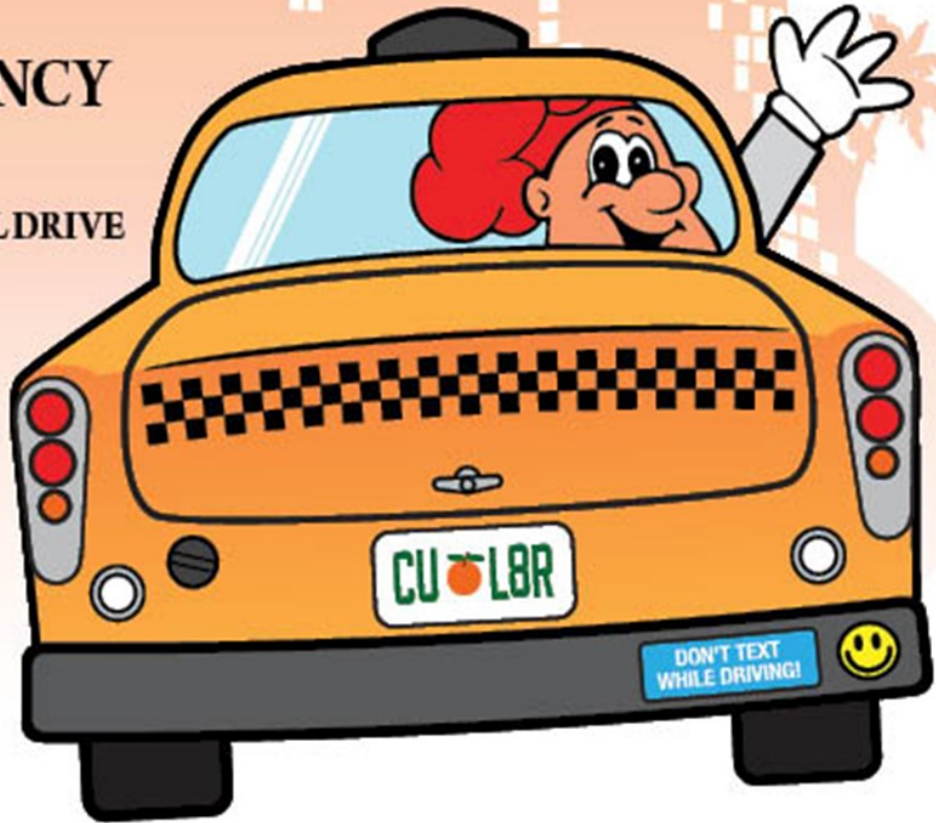
The Family Café is
on Facebook!



Follow us
@TheFamilyCafe



**The
Family
Café**



820 East Park Avenue, Suite F-100 • Tallahassee, FL 32301 • info@familycafe.net