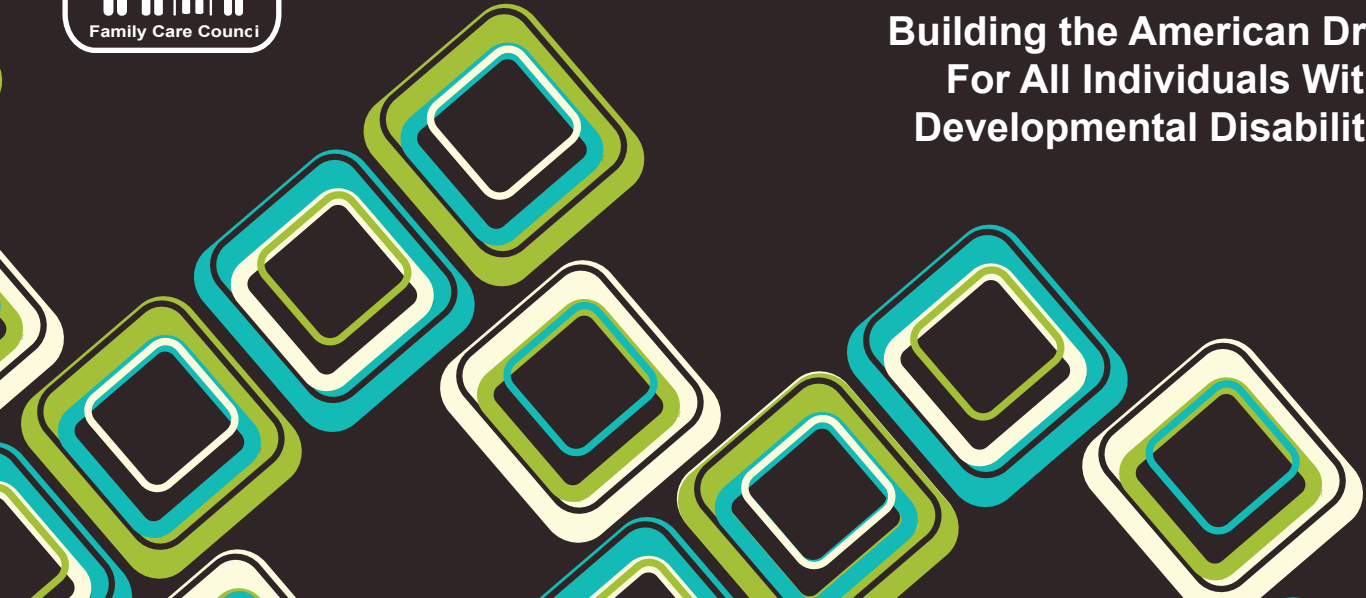


Family Care Council Florida  
WE ARE PART OF YOUR  
**COMMUNITY**



**Building the American Dream  
For All Individuals With  
Developmental Disabilities**



Dear Legislators,

Family Care Councils across the state recognize your continued support to ensure the health, safety, and community participation of individuals with developmental disabilities. Another opportunity is upon us to continue to improve the lives of individuals with developmental disabilities by funding quality services for dignity and choice.

We have enclosed information regarding the mission, purpose, and accomplishments that Family Care Councils have achieved by assisting families to believe in the future.

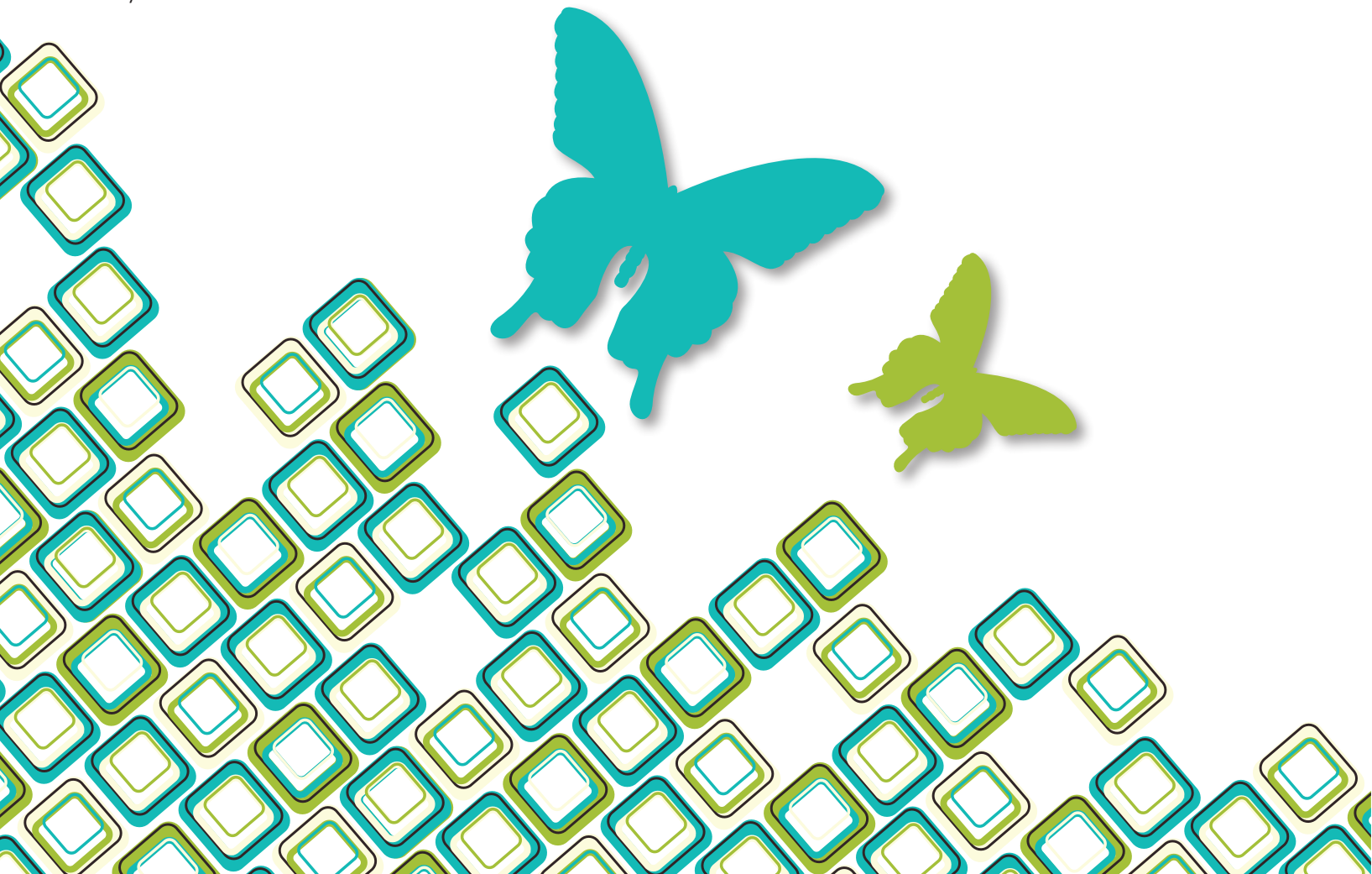
We also have included a few personal profiles that will provide you with a look at how funding has been successful and areas where funding is needed to ensure the health, safety, and community inclusion for some of your constituents who happen to have developmental disabilities.

Should you have any questions about the information provided, please contact us at 1-800-470-8101 or visit our website at [FCCFlorida.org](http://FCCFlorida.org).

Many thanks,



Mary A. Smith



## FAMILY CARE COUNCIL FLORIDA

### Mission Statement:

The mission of the Family Care Council Florida is to advocate, educate, and empower individuals with developmental disabilities and their families, partnering with the Agency for Persons with Disabilities (APD), to bring quality services to individuals for dignity and choice.

### FCCF 2015-2016 REPORT

#### *F.S. 393.502 Family Care Council (FCC) Accomplishments Summary*

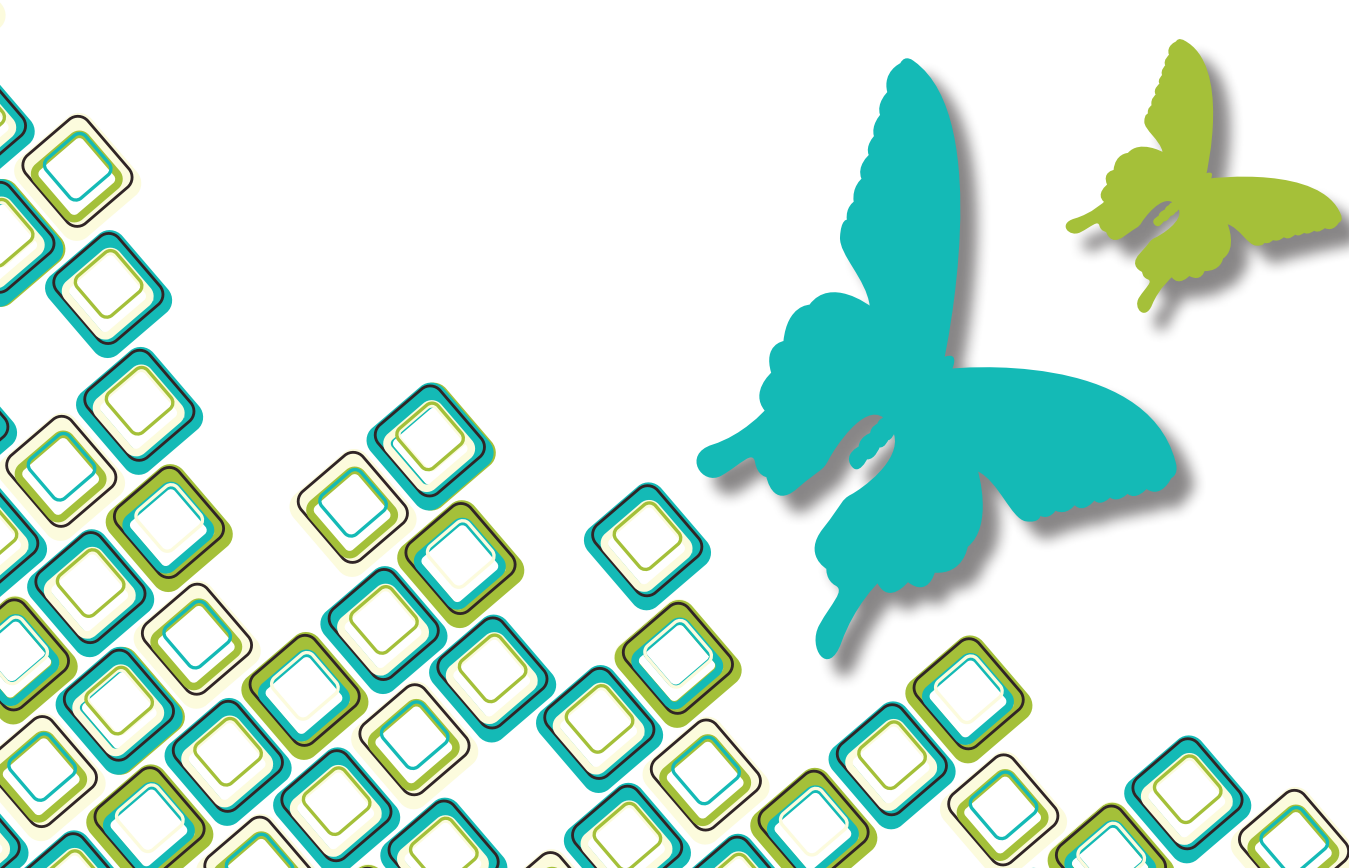
There are 15 FCCs around the state that have as their purpose and primary functions to:

- Advise the Agency for Persons with Disabilities (APD)
  - Develop a plan for the delivery of family support services within the local area
  - Monitor the implementation and effectiveness of services and supports
  - Provide education and outreach to families
  - Review and make recommendations as to the effectiveness of the delivery of supports and services
  - Advocate for local community and family needs
- ◀ Through Family Care Council Florida (FCCF), area FCC representatives met bi-monthly, fulfilling Section 393.502, F.S. mandate to meet and share information between APD Regional/Area Family Care Councils. Conference calls to update and promote discussion were held in addition to the bi-monthly meetings as issues warranted. FCC members mentor other FCC members individually and at FCCF meetings.
- ◀ Area FCCs thanked Legislators and Florida Governor Rick Scott for funding APD at \$1.31 billion for the upcoming year, a \$100 million increase over prior years, to serve Floridians with developmental disabilities; the creation of the ABLE Act; and \$2.5 million for 55 individuals identified with the developmental disability of Phelan-McDermid syndrome. Provider rate increases approved this year were acknowledged to assist with quality and choice for waiver participants.
- ◀ Area FCCs have experienced membership growth in the past two years. Each FCC has actively recruited and recommended applicants for their local FCC, and Governor Scott has appointed 18 new members and reappointed nine members to FCCs across the state.
- ◀ Area FCCs held regularly scheduled and advertised monthly meetings averaging 10 meetings per year for each council, as required by Section 393.502, F.S., and adhering to Florida Sunshine laws.
- ◀ Area FCC meeting agenda examples include: FCC business items, budgetary items, bylaw review and updates, action/support plan items, committee reports, the Chair's FCCF meeting report, public outreach activities report, a calendar of local events, APD updates by regional APD staff, and time for public comment.



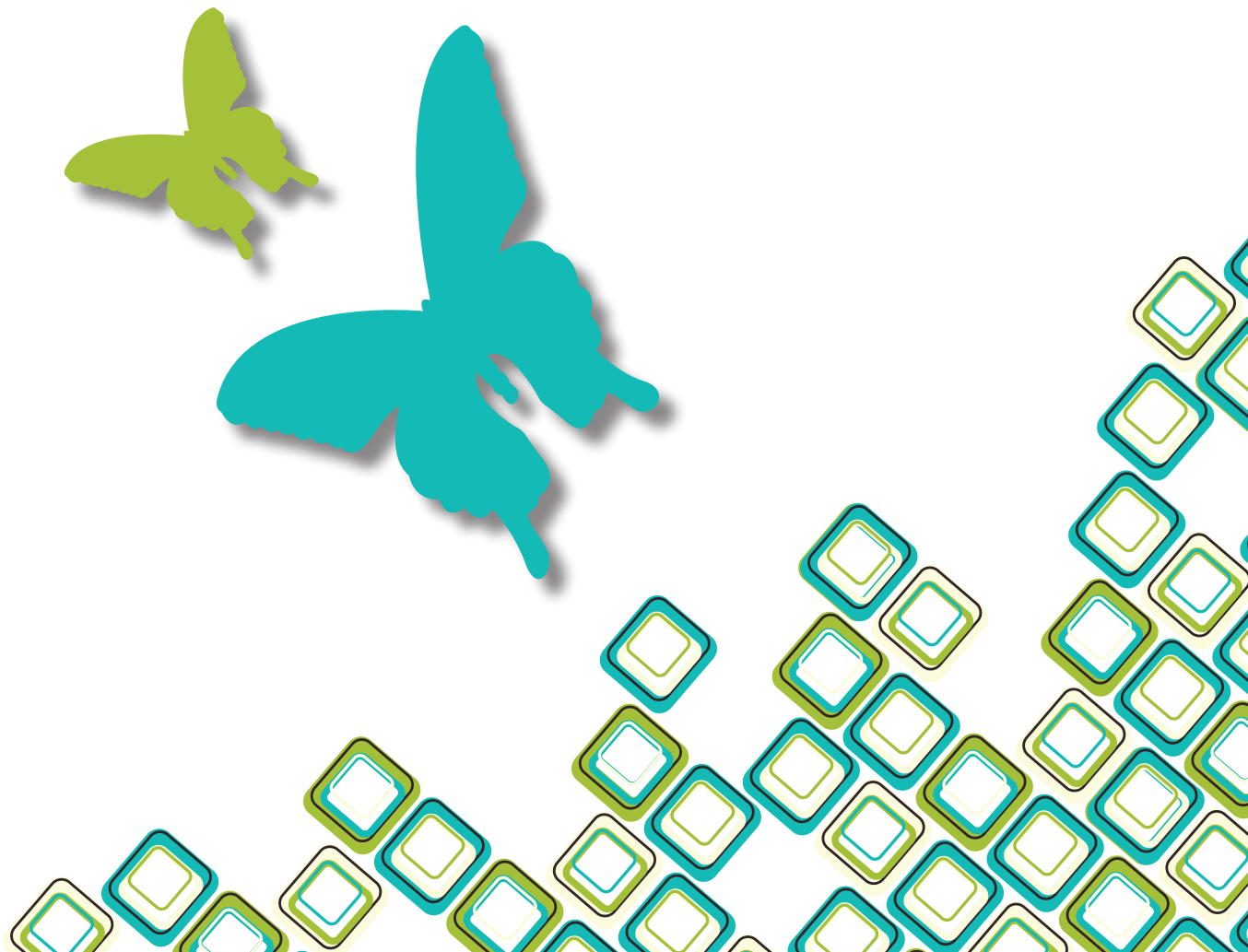
Area FCCs accomplished the following:

- Visited with legislators in their home offices, at local delegation meetings, and at the FCC display booth in Tallahassee during Developmental Disabilities Awareness Day.
- Developed and supported legislative platforms for issues affecting individuals with developmental disabilities and their families.
- Submitted the personal stories of individuals receiving and waiting for waiver services for inclusion in the “Community Profile Booklet,” which was distributed to all legislators and used for community education and outreach.
- Responded to a total of 218 inquiries from the community (via the FCCF maintained toll free number) and numerous personal contact/emails from Floridians requesting information on services, supports, waiting list, waiver issues, and community resources that are available or needed. FCCs provided information and referrals for these community questions.
- Attended and participated at APD trainings and APD provider and waiver support coordinator meetings.
- Served on the Delmarva Quality Council and local active Quality Steering committees.
- Hosted local family forums, conferences, workshops, meetings, and events with a diverse agenda of topics for education and outreach to individuals and families. Resource fairs were held, and the APD waiting list, housing, employment/benefits, ESE and ESE-Transition, iBudget, guardianship, wills and trusts, and behavioral issues were among the top agenda items. Several FCCs partnered with local organizations and state/federal agencies to address pertinent community issues. During these events, FCCs distributed a variety of brochures related to specific disability groups. Through these events, FCC is able to cultivate and increase their mailing and email contact lists for future community outreach.
- Participated in APD QSI conference calls, FDDC Abuse and Neglect Workgroup and monthly stakeholder calls, AHCA, DOE, FND, APD Waiting List Implementation Task Force, Waiting List Strategic Plan, Medicaid, employment, self-advocacy, WSC issues, CDC+, CMS meetings through conference calls and workgroups, focus group surveys, APD agency rule hearings, and CAFE legislation calls and workshops throughout the year.





- Sponsored families to attend the 18th annual Family CAFE. Members also inaugurated a workshop at CAFE focusing on the mission of FCC, starting with developing a PowerPoint, selecting members to speak, and distributing resource information. FCC members also manned an exhibit booth throughout the weekend providing assistance with registration and other volunteer activities.
- Posted on FCCF's social media site.
- Participated in various conferences, events, and meetings, including Housing Coalition; Residential Options of Florida; VISIONS; AAIDD; Arc; Special Olympics; FDLRS; Easter Seals; PTI; CFPC and COPAA (Council for Parents, Advocates and Attorneys) that provides webinar training to support and educate individuals with disabilities, families, Waiver Support Coordinators, Waiver Consultants, and Guardian Advocates; Department of Education ESE Superintendent's District Advisory Panel; Exceptional Student Education Conference; Family Community Involvement Advisory Council (FCIA); meetings by stakeholder organizations such as FARF, The Arc of Florida, NAMI, and Lifespan Respite; Carlton Palms Quarterly meetings and CMS Rule issues and Transition Planning; Person Centered Planning; Florida Symposium on Aging with Developmental Disabilities; Youth Summit; SNAC; Disability Mentoring Day; Disability History and Awareness Month; Department of Elder Affairs/No Wrong Door; Americans with Disabilities Act celebrations; FDOA Sportsability; CARD; FDDC and Autism Speaks; and Buddy Walks.
- Promoted and encouraged the organization of support groups and participated in self-advocacy groups such as Florida SAND, along with assisting with the CDC+ support group.
- Engaged in webinars including FDDC, FARF, Job Accommodations Network, Employment First Florida, CAFE Fridays, Crisis Services and Community Integration, Supportive Decision Making, iBudget Waiver Provider Rate Crisis, and the Home and Community-Based Setting Rule.



## Ben Howard

Diagnosed with autism at age 3 and on the Medicaid waiting list for waiver services by age 4: Ben Howard's struggle to get state support is not uncommon. Like many other families in similar situations, Ben's parents turned to the school system for help, therapies, and guidance, but he struggled with sensory overload and was unable to communicate in words what he was experiencing. His anxiety and extreme behavior led to in-home placement, where he remained for several years.

Ben's family lives in a rural area, meaning additional therapies were always too far away to access with only one car for the family. Additionally, many providers who could have helped Ben would not accept Medicaid State Plan. In working with Ben, the focus shifted more to controlling behaviors than teaching him basic communication skills. His family and teacher were lost

as to how to best teach Ben the skills he needed most. Eventually, the school recommended an institution for Ben. His father was at a loss of words.

Finally, Ben's father turned to the connections he had found through the Family Care Council. There he found a network of other parents, community connections, and statewide advocates like Family Network on Disabilities and Disability Rights Florida who understood his situation and were willing to help. Through their guidance and advocacy, Ben got the help needed to let him return to public school.

Today, Ben is happy to attend school and venture out into the community, and he is slowly finding his voice. His father hopes that someday Ben will qualify for full waiver services to get the additional help he will need to succeed in the community.





## Micah Hohney

My name is Micah Hohney, and I am 23 years old. I use an electric wheelchair because I have cerebral palsy. I came on the iBudget Florida Medicaid waiver through the crisis process about a year ago. I had been on the waiting list for some time. My mom took care of my personal needs such as cooking and laundry.

My mom then decided she was moving to Texas, and I was supposed to go with her. However, I had started the PALS program at Pensacola State College and wanted to stay in Pensacola to finish the program.

My mom left for Texas sooner than expected, and I suddenly found myself alone in the apartment. Since I had no family here, my crisis packet was approved quickly, and I moved into a house with personal supports and a supported living coach. I will graduate from the PALS program in December, and I plan to continue my education at Pensacola State College. I want to work in either IT or aviation.

My interest in aviation has grown as I've taken flying lessons at the Pensacola Airport, logging over 30 hours so far on a Cessna 172. I like flying because I am in control and only need a little help with landing; I can forget about being disabled. I even took my dad flying with me when he came for my surgery in May.

With the help of the waiver services, I am living the life I want, making many acquaintances, and have many plans for the future. I have been researching cars modified for drivers who use wheelchairs. Without the waiver services, I would have had to leave Florida and leave my dreams behind. I believe that if you can dream it, you can do it, although it may take some assistance from others.



## Michael Ingram

My name is Michael Ingram, and I have always been a very determined person. I wanted to get a job in my community that I enjoyed, and I went to all sorts of employers before I finally got the chance to interview at Walmart in Pensacola, my current company. Previously, I got told 'no' a lot, but I remained persistent and determined not to get discouraged. I was ready and willing to work, but I just needed a chance to prove myself. When my job coach came with me to ask employers about jobs, many recognized me because I had already come in to meet them and see about a job. My job coach helped with my resume, interview skills, and maintaining a positive attitude while we searched for employment.

I am so happy and proud that I was able to begin working at Walmart and show my abilities. My job duties include sweeping aisles, cleaning spills, and

ensuring the overall cleanliness of the store. My manager has been great so far, and while I have only been employed there for a few months, they have welcomed me and made me feel like a part of the team!

My goal is to go back to school someday and learn how to write programs for video games. My job has allowed me to start saving for school and has given me the security to be able to pay my bills each month with some left over for myself. I am thankful for the opportunity to work and learn new job skills. I am comfortable in my job and feel confident that my job coach can help me with job related issues or concerns. I hope to remain employed for as long as possible, and I vow to never give up after such a long journey towards finding this great job!





## Darryl F. Bonet

My name is Darryl, and my story began when I was born in Puerto Rico 20 years ago. When I was born, I was diagnosed with microcephaly, and doctors told my parents that I wasn't going to be very active in life. Through the love and support of my parents, my siblings, and God, I proved them wrong. I was able to do what every other kid was capable of doing. Of course, I have severe developmental delays, including speech issues. Even though I'm 20 years old, I still think like an 8-year-old boy.

I have many interests and hobbies that I enjoy doing. My favorite thing to do is to visit the Kennedy Space Center. I also love all sports, but my favorite is baseball. I am a player for Tri-County Challenger Baseball League. Everyone agrees I'm great at the bat and can

run really fast. I graduated this year from North Ft. Myers High School, but I'm still academically active at my school. I belong to JROTC, and Sergeant Major Lansberry has taught me a lot all these years. Also, I am a sweet heart when it comes to homecoming dances because girls like to dance with me.

My family is considered blessed with me in their lives, even though I can drive them crazy sometimes. I know I'm not easy to handle, but their love, patience, and wisdom have kept them strong all these years. I'm grateful they made the wise decision to move to Florida. I'm truly blessed beyond measure.





## Levi Ballard

Levi's life has not been an easy one, even from the start due to birth complications. He started sitting up and walking later than most, and he never learned necessary daily self-help skills. Thankfully, his mother has always helped keep him clean and healthy. Now, he can dress himself if there are not buttons or shoe laces involved. Sometimes, he will put his shoes on the wrong feet, but his mother is there to fix them for him. He is unable to read, write, or talk.

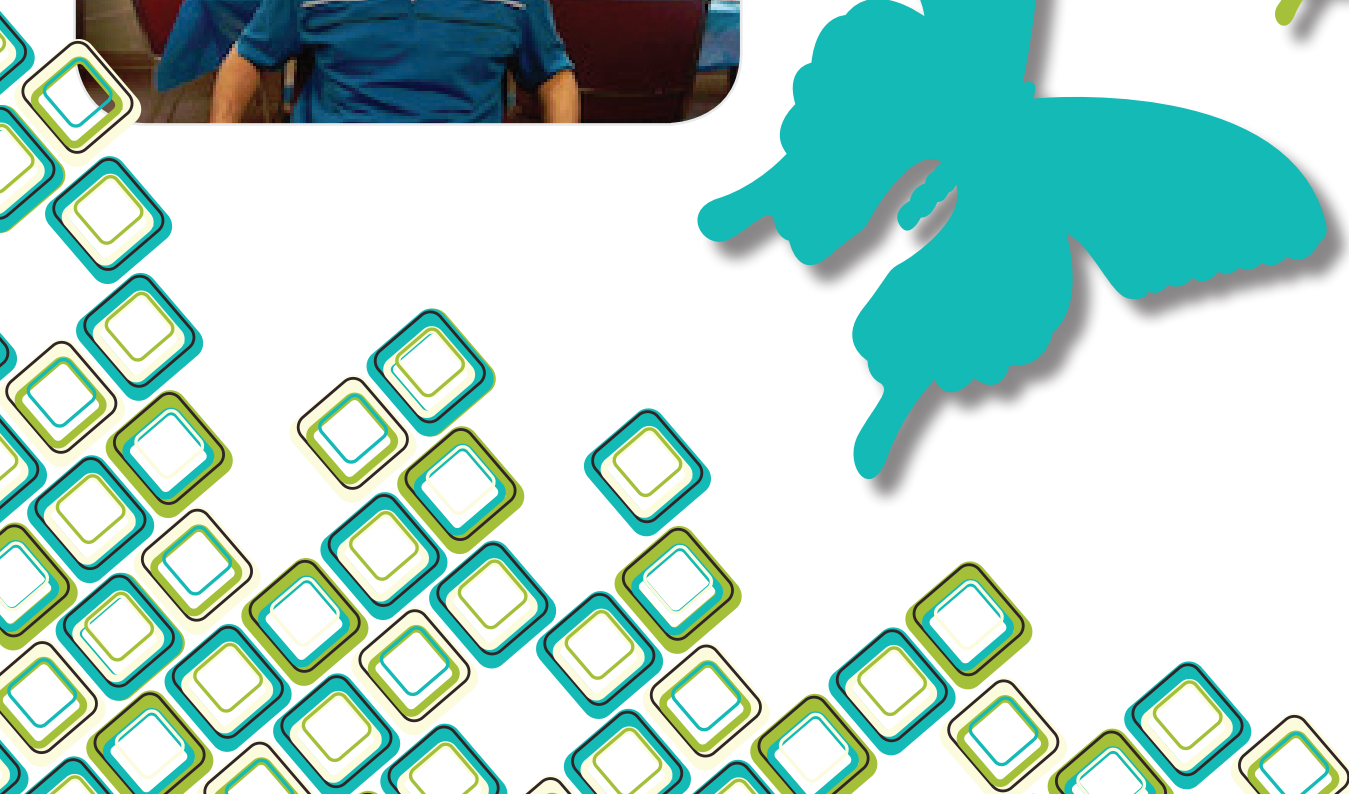
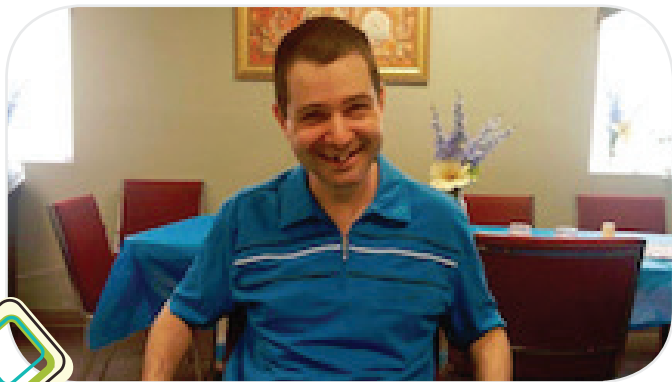
According to Levi's mother, he usually doesn't cooperate with learning tasks, instead doing the opposite of what he was supposed to do. Levi also has epilepsy, which causes him to have grand mal seizures. He is taking medication for them, which has decreased their frequency greatly. Otherwise, he has excellent health.

Still, Levi enjoys many things life has to offer. He has a healthy appetite and loves to eat most everything. He likes to walk, go shopping, and go to church to see

the people, although sometimes he can get noisy and disruptive.

Levi's mother also recounted some of his lovable quirks that make him unique. He loves to carry anything he can find in a small travel bag he has had since starting school that he brings everywhere. His mother described some of the odder things Levi has picked up, including melted popsicles, overripe fruit, and open cans of Coke. His favorite item, however, is batteries; he gets a new package every week when his mother takes him to the store.

Despite all this, Levi and his mother wish for an opportunity for him to interact with people he is comfortable with. He doesn't have many activities to do during the day and would greatly benefit from a day program with activities and socializing. Levi's mother says that he can learn to stay on task if someone can keep him interested.



## Cameron Wingate

My name is Cameron Wingate, and I'm 36 years old. I have been on Florida's CDC+ Medicaid waiver since 2008. I have autism and live on my own on the Treasure Coast, near my family and friends.

I started my first job while still in high school, and I continued to work and grow there for 13 years. Three years ago, I began a new job and am learning new skills and setting goals for success.

The money I receive from CDC+ is used to buy in-home services that help me learn how to grocery shop, cook, eat well, exercise, and take care of my home. I buy a discount dental plan so my CDC+ savings stretches farther for dental care. Because I have worked, I have SSDI that gives me Medicare health coverage, which is the first payer for counseling; this also helps save CDC+ money.

My in-home support worker also helps me get to know new people and be comfortable with community activities.

My dad also works with me, teaching me how to live within my budget and manage my personal money. When this goal is reached, I'll start learning how to oversee my CDC+ finances and plan to represent myself.

I started therapeutic horseback riding in 2010, and it helps with many goals in my support plan. In 2012, I started volunteering at the same barn, supervised by the staff, helping others improve their physical

and mental health. Special Equestrians of the Treasure Coast charges a greatly reduced fee for a half-hour of PATH-certified equine therapy. They receive funds from donations, fundraising, and grants, so it isn't as expensive as other certified therapeutic stables.

Bowling also helps with the community integration part of my support plan. The owner gives us a reduced rate when we come in to practice with friends and family.

With CDC+, I can shift services and providers as my needs change. I can get more support in one area and less in another as long as the services meet my goals and are within my assigned budget.

Natural supports are important to my success. My dad does my taxes for me for free and helps maintain my car. My mom works as my Social Security representative payee and as representative for CDC+ as an unpaid volunteer.

I enjoy Special Olympics sports during the year such as bowling and competing in equine events. There is no charge for these Special Olympics sports during the season.

Finally, I'm a member of the Center for Autism and Related Disorders, and we meet every month for social activities. CARD provides the counseling and guidance for this community-based group.



## Richard Carlton

Born in a car on the way to the hospital, Richard Carton experienced a lack of oxygen at birth. This has resulted in both developmental delays and mild cerebral palsy.

Richard has made the best of his abilities throughout his 59 years of life. He was a student of the Marian Center, the special education division of the Archdiocese of Miami, from ages 12 until 18. Richard loved his time there and didn't want to leave – so much so that he took a full-time job at the school as a janitor/groundskeeper for 26 years.

Sadly, Richard's parents both died of cancer within a two-year period, causing him to move to Tallahassee to live with his brother and sister-in-law at the age of 45.

Since relocating to Tallahassee, Richard has been receiving Social Security Disability Insurance for his disability while working part-time. He worked at Publix as a bag boy for some time until he had eye

surgeries and vision loss, making him unable to safely manage the parking lot. He is currently doing part-time janitorial services at Pyramid Studios.

Richard has been a student at Pyramid Studios for the last 10 years, developing talents in singing, acting, and painting. Richard is even currently playing the trombone in the Pyramid rock band.

At age 59, Richard has just obtained his apartment at Casa Calderon for persons with disabilities. He was on the APD waiting list from 2002 through 2016 and is now receiving waiver services. Since 2013, has had the honor of being appointed by Governor Scott to the Family Care Council. Through this role, Richard continually advocates for others currently on APD's waiting list.





## Daniel Bayley

I want to ask the Florida Legislature to approve more dollars to help the Agency for Persons with Disabilities (APD) eliminate the waiting list so other citizens can receive the services they desperately need to be safe and happy Floridians.

APD has helped make my goals realities. From 2009 until 2016, I was on the waiting list for services. I finally got on the iBudget Florida waiver in 2016, and I am currently the Chair of the Area 7 Family Care Council, an advocating organization to promote services for individuals with developmental disabilities. It took a few weeks to transfer from the waiting list to iBudget,

but now I am working with two aide service agencies to provide me assistance to continue to live safely at home.

All of this is on top of fulfilling my dream of living in sunny Florida!

I have a wonderful service coordinator who knows my needs and is working closely with APD. Barbara Palmer, Director of APD, has been advocating to serve the waiting list for several years. She and APD need more dollars so every Floridian with a developmental disability can live safely and achieve their own goals.





## Matthew Hurst

My name is Matthew Hurst, and I am 23 years old. I am the proud owner of Matthew Hurst Enterprises, a micro-enterprise business. With the support of Vocational Rehabilitation, I was able to build and grow my business, which was inspired by my love of video games. I worked hard with my mom, family, and coaches to develop a business that not only would be something that I enjoy, but also would allow me to make money and work in my community. Through my hard work and dedication and support from those around me, my video and arcade game ideas have come to fruition; they are available at the local skating rink, where I am responsible for maintaining the games with the help of a job coach.

This journey to realizing my dreams wasn't always easy. I was diagnosed with autism when I was young

and have challenges communicating with others. For the past few years, I have used an electronic communication device that helps me express to others what I want and how I am feeling. I also attend speech therapy, which is where the picture of me was taken. Communication was an essential part of starting my business, so the support I have received has been very helpful. With therapy, my device, and my job coach, I am well equipped for success.

I live with my mother and help out around the house by doing various chores, such as laundry and putting away silverware. In my free time, I enjoy looking at books and magazines, watching movies, and spending the money I earn from my business at book stores.





## Whitney Jordan

My name is Whitney Jordan, and through hard work and the support of APD, I just purchased my own car! Let me tell you how it all started.

Over two years ago, I selected someone from APD to assist me in the area of supported employment. For a few months, we worked hard on practicing job skills, practicing interviewing skills, creating a resume, and applying for several jobs. My job coach often said, "Hard work pays off." She was right! On December 8, 2016, I will celebrate being employed for two years as a custodian at the Naval Aviation Station in Pensacola, Florida.

I have really enjoy getting to know my co-workers and supervisors. This job allows me to go to different buildings and meet different people, but, most

importantly, it allows me to feel good about myself. I have proven that I have the ability to work hard and reach my goals little by little.

After I started working, my goals were to save money for my own car, to practice driving with my family members so I could pass the driver's license test, and to work hard so I could keep the job that I love. I am proud of all of my accomplishments. I am grateful to my family members, job coach, supervisors, and agency representatives who played a big part in helping me reach my goals. Before I start making a new list of goals, I'm going to get my driver's license! I plan to take the test in February of 2017. Wish me luck!



## Mary Smith

Having a child with developmental disabilities was an unplanned event. We did not know about the difficult challenges we would face. We received Parent Effectiveness Training, a specific parent training covering a broad range of components. We acquired knowledge, skills, and strategies that have been the catalyst for responsive interaction with our children. Parent training positively impacted the quality of our family's life and encouraged an enthusiastic attitude of hope and direction.

Those classes so many years ago set the bar for positive emotional and disciplinary communications that continue to drive our direction as parents. We were able to concentrate on his capabilities, not his deficit, as a child with developmental disabilities. Treating him normally and not "special" gave him the

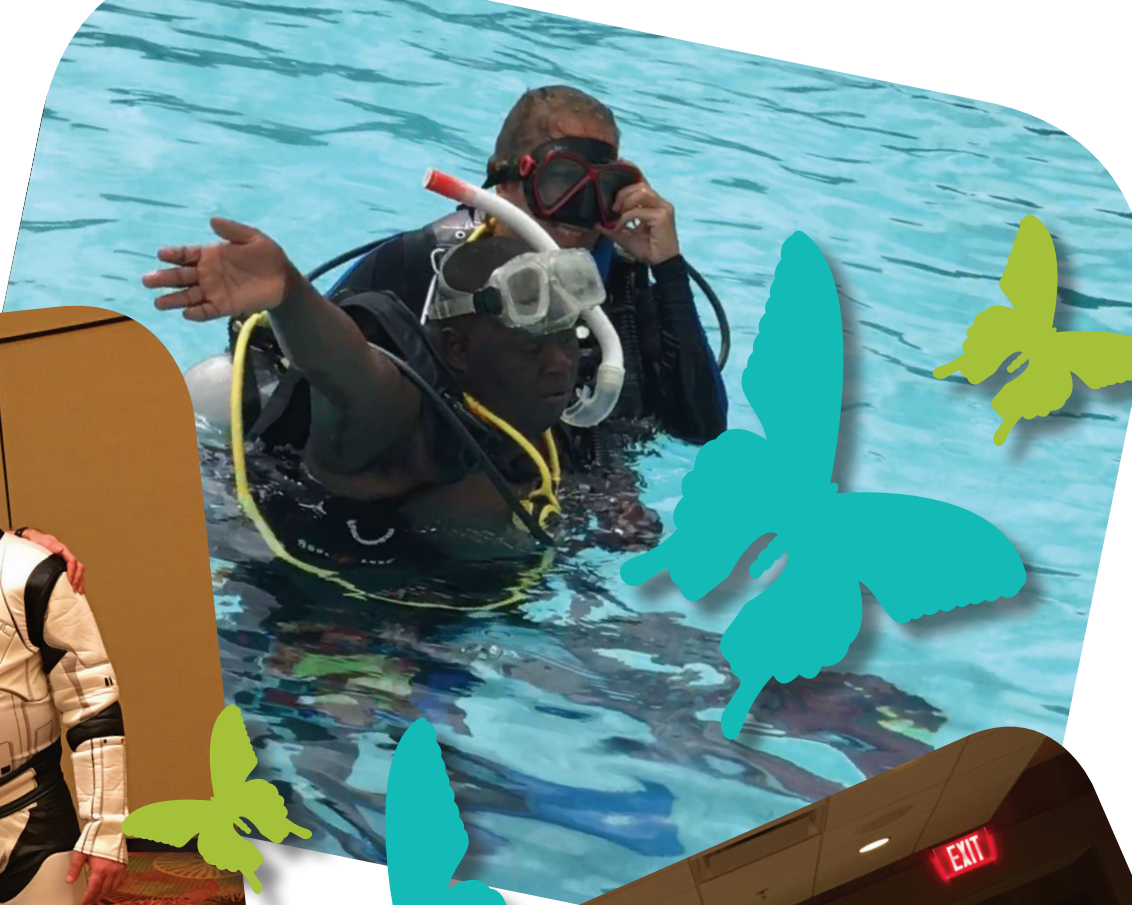
confidence to live a well-rounded life that was not defined by being in a wheelchair, but by his interests.

Families are reaching out for help when they apply for APD Medicaid waiver services. When they are deemed eligible for the waiver, many must wait years for those services. It would be to the state of Florida's advantage to offer parent training. The training tactics learned could help sustain them by identifying coping skills, training methods, and natural strengths to establish hope and direction for overall family stability.

As chairperson for Family Care Council Florida and a mother who has walked the walk, I believe parent training is critical to establish hope, direction, and family stability for those on the waiting list, as well as preparing them to receive services.

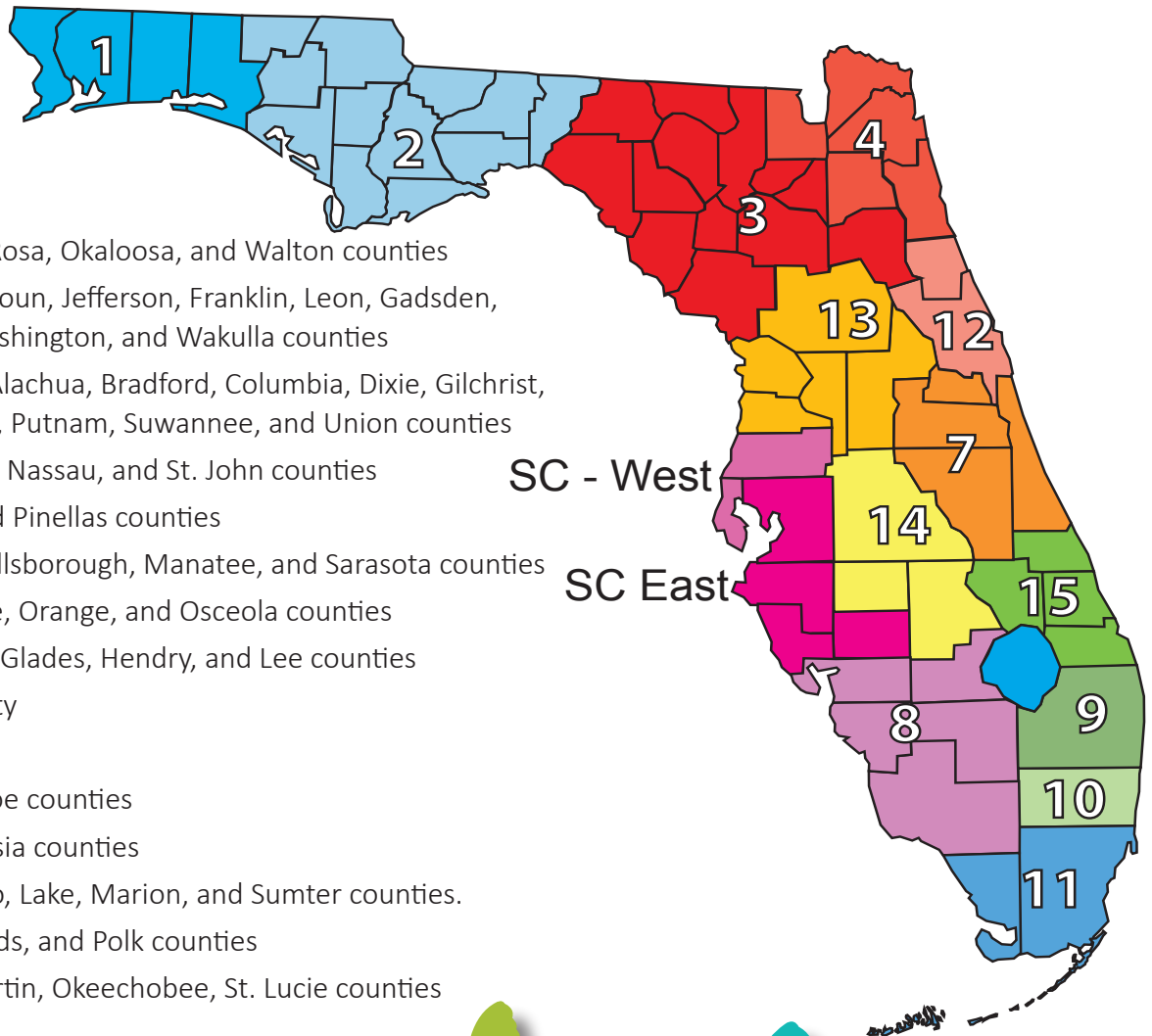




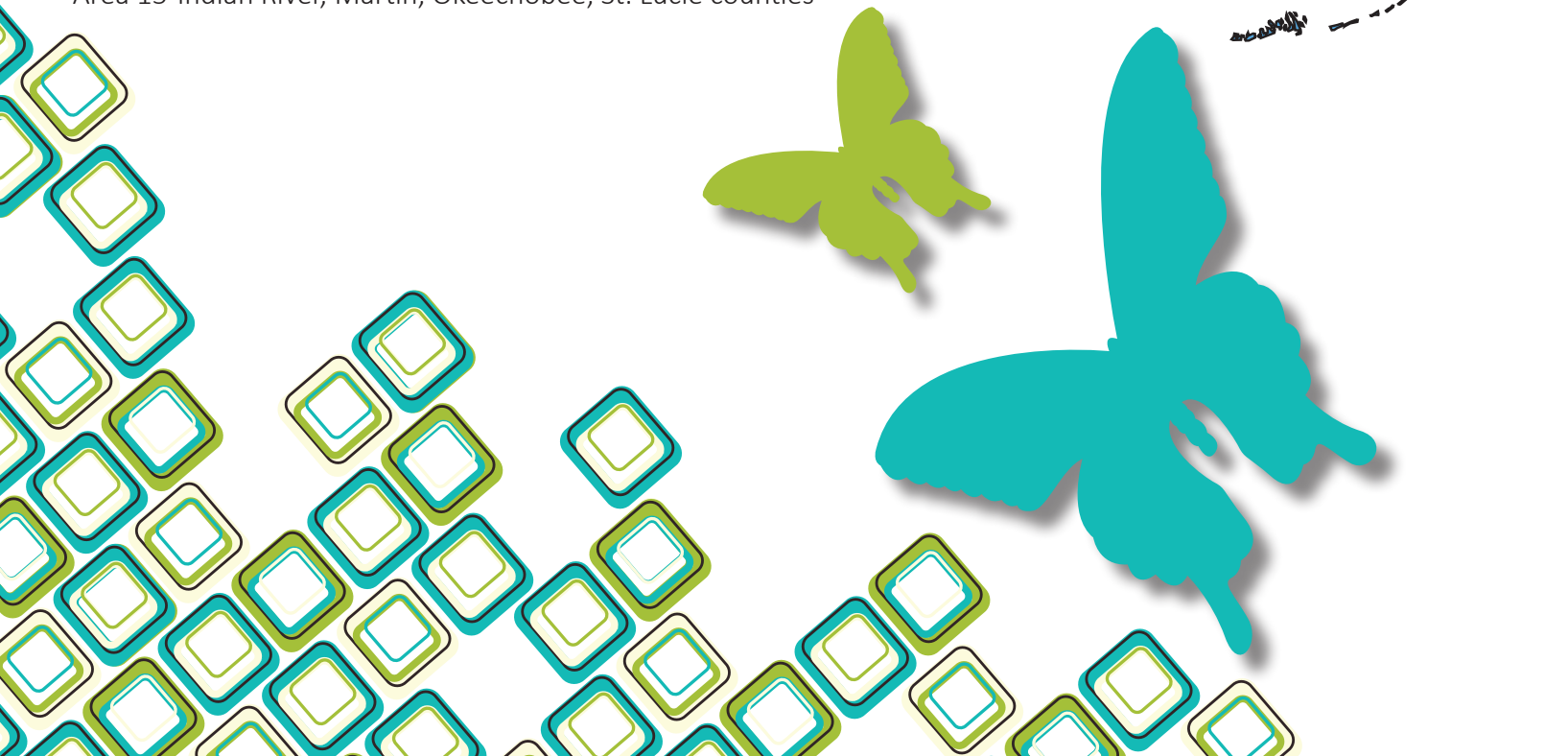




# Local Family Care Councils



- Area 1-Escambia, Santa Rosa, Okaloosa, and Walton counties
- Area 2-Bay, Jackson, Calhoun, Jefferson, Franklin, Leon, Gadsden, Liberty, Gulf, Holmes, Washington, and Wakulla counties
- Area 3-Madison, Taylor, Alachua, Bradford, Columbia, Dixie, Gilchrist, Hamilton, Lafayette, Levy, Putnam, Suwannee, and Union counties
- Area 4-Baker, Clay, Duval, Nassau, and St. John counties
- Suncoast West-Pasco and Pinellas counties
- Suncoast East-DeSoto, Hillsborough, Manatee, and Sarasota counties
- Area 7-Brevard, Seminole, Orange, and Osceola counties
- Area 8-Charlotte, Collier, Glades, Hendry, and Lee counties
- Area 9-Palm Beach County
- Area 10-Broward County
- Area 11-Dade and Monroe counties
- Area 12-Flagler and Volusia counties
- Area 13-Citrus, Hernando, Lake, Marion, and Sumter counties.
- Area 14-Hardee, Highlands, and Polk counties
- Area 15-Indian River, Martin, Okeechobee, St. Lucie counties









**Family Care Council Florida**

**P.O. Box 300100**

**Fern Park, FL 32730-1000**

**Toll-Free 1-800-470-8101**

**(English and Spanish operators available)**

**[FCCFlorida.org](http://FCCFlorida.org)**