

Family Care Council Florida
WE ARE PART OF YOUR
COMMUNITY

Family Care Council Florida
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(English and Spanish operators available)
FCCFlorida.org



Working Toward Building The American Dream For All
Individuals With Developmental Disabilities



Family Care Council Florida

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West

Nancy Simmons

Area 7

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Area 8

Patricia Oglesby

Area 9

Karen Oberg

Area 10

Gilda Pacheco

Marty Norris

Area 11

Rosa Maria Barbara

Area 12

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Greetings!

Family Care Councils across the state wish to acknowledge the essential role that your support provides to ensure the safety, health, and community participation of people with developmental disabilities in Florida.

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

We have also enclosed a few personal profiles that were published in the 2014 booklet called, "Interesting Floridians You Should Know". It will provide you with a glimpse into the lives of 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.

Sincerely,

Pauline S. Lipps

Pauline S. Lipps
Chairperson

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, to bring quality services to individuals for dignity and choice.

LEGISLATIVE PLATFORM 2015

Family Care Council Florida (FCCF) is comprised of individuals with developmental disabilities and their families. We are committed to educating, advocating for, and empowering every Florida family having a member with a developmental disability. From our collective experiences, we have identified the following 2015 Legislative issues:

We believe the iBudget is working and it remains the best option for containing costs, providing choices and flexibility for the needs of individuals in a safe environment within the community. To ensure its continued success adequate funding must be appropriated:

- **To meet the requirements of the new CMS rule and Minimum Wage regulations**
- **For adequate training and retention of direct care staff**
- **To ensure person-centered planning for all ages**
- **To reduce the risk of abuse, neglect and exploitation by enhanced training and supervision**

We advocate for the active elimination of the Agency for Persons with Disabilities (APD) iBudget waiver waiting list, and urge the Legislature to approve substantial additional funds for this purpose.

We support the APD request for authorization to fill vacant positions needed for the oversight of services to ensure the health, safety and welfare of the individuals served by the agency.

We believe that continued funding for the APD Employment Enhancement Project and the Governors Employment First initiative is important to individuals with developmental disabilities.

We support the 2015 funding of the Arc of Florida's Dental Project that has successfully recruited dentists and provides dental care necessary to the health and self-esteem of individuals with developmental disabilities.

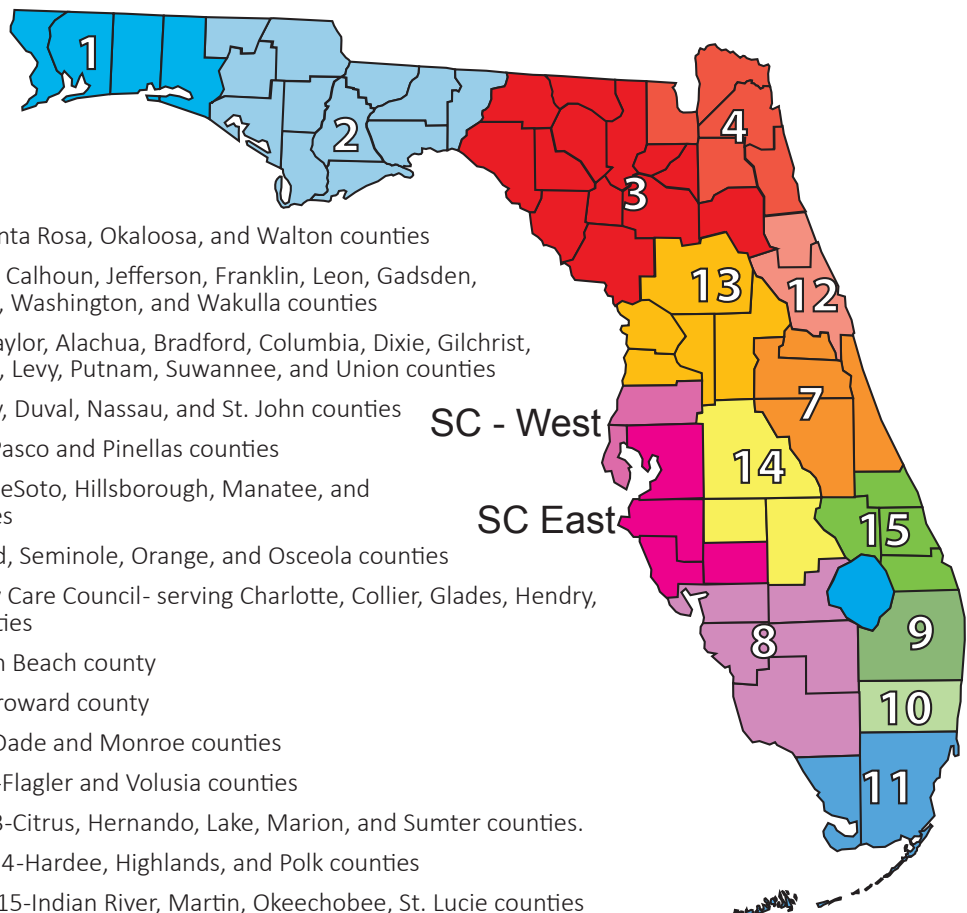
Family Care Council Background

In 1993, the Florida Legislature created the Family Care Councils (Section 393.502, Florida Statutes) in each service area of the Agency for Persons with Disabilities (APD) to advise the agency, develop a plan for the delivery of family support services within the local area, and monitor the implementation and effectiveness of services and supports provided under the plan.

While APD has the responsibility for the welfare and dignity of individuals with developmental disabilities, the Family Care Councils (FCCs) are governor-appointed volunteers who advocate for people with developmental disabilities and their families. There are 15 local FCCs throughout the state. Each council is made up of 10 to 15 members which reflects the geographical areas and the various disabilities, ethnicity, and ages served by the agency. The membership is comprised of individuals with developmental disabilities, parents, siblings, grandparents, and guardians of people with developmental disabilities who qualify for APD services. In addition, each council is independent from the others. Most FCCs are active with other local organizations and partner to provide community forums, events, and conferences to benefit individuals with developmental disabilities and their families.

Through the Family Care Council Florida (FCCF), representatives from each FCC meet bimonthly to educate and discuss common concerns while working together to represent individuals with developmental disabilities and their families as a united voice.

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 Family Care Council- serving 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

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 2013-2014 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;
 - Meet and share information with other Family Care Councils.
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- 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 FCCs. Conference calls to update and promote discussion were held in between the bi-monthly meetings as issues warranted. FCC members mentor other FCCs individually and at FCCF meetings.
 - Area FCCs thanked Legislators and Florida Governor Rick Scott for legislation that expands the membership of the FCCs to now include grandparents.
 - 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 more than 100 members to FCCs across the state.
 - Area FCCs held regularly scheduled, advertised, monthly meetings averaging 10 meetings per year for each council, as required by Section 393.502, F.S. and Florida Sunshine laws.
 - Area FCC meeting agenda examples include: FCC business items, budgetary issues, bylaw reviews and updates, action/support plan items, and APD updates by Region/Local APD staff.

Area FCC Activities and Accomplishments

- Hosted APD Director Palmer and collaborated with APD on 17 Town Hall events across the state, to listen to issues and concerns of families and providers, and to assist APD future planning. Governor Scott attended several of the events.
- Visited with Legislators in their home offices, at local delegation meetings and in Tallahassee at DD Day. Developed or supported legislative platforms for issues affecting individuals with developmental disabilities and their families. Facilitated procurement of individual stories for the FCCF profile booklet distributed to all legislators, and for community education and outreach.
- Hosted Local Family Forums and/or FCC conferences with a diverse agenda of topics for education and outreach to individuals and families. Resource Fairs were held and APD waiting list, housing, employment/benefits, ESE & EES-Transition, iBudget, guardianship, wills and trusts, and behavioral issues were among the top agenda items. Several FCCs collaborated with local organizations for community events on pertinent issues.
- Assisted with planning and participated with APD in holding a Lifespan Respite Summit to explore establishing a coalition for a State Lifespan Respite program. Activity on this significant initiative is going forward.
- Participated on APD, FDDC, AHCA, CMS and other related workgroups, iBudget handbook, rule hearings and workshops held throughout the year.
- Sponsored, or attended various conferences and events regarding Housing Coalition, VISIONS, AAIDD, Arc Conference, Autism, Down Syndrome, Managed Care, Special Olympics, FDLRS, Easter Seals, meetings held by DD stakeholder organizations such as FARF, FND, The Arc of Florida, FDDC participating in activities, and workshops.
- Served on APD Quality Council and local active Quality Steering committees.
- Sponsored more than 25 families to attend Family Café. FCC members also attended, with several FCC members assisting with the FCCF exhibit. A few members assisted with Café registration and other activities as well.
- Responded to messages for their local area (via the FCCF maintained toll free number) from people requesting information, resources or other issues. Approximately 100 calls were received and responded to by a local FCC member.
- Received many calls and emails from individuals, family members, community organizations, healthcare offices and others with questions about services and supports available for families, waiting list and waiver issues, and community resources available or needed. Information and referrals made as indicated.
- Outreach by Area FCCs occurred in several ways: An FCC participated in two separate local radio call-in shows; articles in local newspapers; Facebook and other social media set up with postings; brochures or articles posted on local community and office bulletin boards; fact sheets prepared and circulated; local website and resource libraries developed and updated.

- Distributed newly updated FCCF brochures. Several Area FCCs also designed and distributed local-specific FCC brochures.
- Attended and participated at APD trainings, and APD provider and waiver support coordinator meetings.
- Promoted and encouraged the organization of support groups and participation with self-advocacy groups such as Florida SAND. Local members assist CDC+ support groups in several APD/FCC areas.
- FCCs cultivated mailing and email lists for broader distribution and outreach.



APD Waiting List Families

Daniel Bayley, Brevard County

Hi everyone. I wanted to explain my situation here in Florida. When I moved here in 2009, with my friend and caregiver, I was told that I would need to wait seven years or more for services through APD! Even basic services! I live a full and happy life now because my friend helps me with everything I need. I cannot do anything for myself because I have had mild to moderate Cerebral Palsy since birth. I am now 41. I need help with eating, dressing, and personal hygiene. I use a power wheelchair that I operate with my chin. Also, most people do not understand me because of my speech impediment.

I don't know what will happen to me if my caregiver can no longer provide the care I need. It scares me to think what will happen to my full and happy life here in Florida. Does Florida realize that there are thousands of "me's" who are profoundly concerned how we will be cared for in our future? Someone once said that a civilization is judged on how it teaches its youth and how it cares for its elderly and people with disabilities. How will Florida be judged?



Caleb Prewitt, Duval County

Caleb Prewitt is 7 years old. First of all, he is ALL BOY and loves all cars and sports. Caleb attends school at the North Florida School of Special Education. He loves to read, and will read aloud to you, if you ask him!

Besides being an active young man, Caleb loves to interact with people. He's not met anyone who isn't a friend. We feel Caleb has a bright future in store for himself. Caleb joined the APD waitlist approximately four years ago. We have received some products from surplus funding (pull-ups).



Additionally, with our involvement in the Family Care Council Area 4, we have received assistance to travel/attend the Family Café in recent years. We have been able to meet people in various disability fields who have been helpful.

Emmanuel Oglesby, Lee County

When I was born I had two holes in my heart. The doctors fixed me up and “Thanks be to God” I have not had any heart problems since. I live with my mom and my older brother in North Ft. Myers. My dad is gone on to be with the Lord. I’m currently 14 years old and I attend Mariner Middle School. School is the highlight of my day, along with the bus ride. I have received the Academic Achievement Award two years in a row from President Obama. Here are some of the programs that I am involved in:

- Anti-Bully Club
- Dance Club
- Youth Ministry at church
- My favorite sports are soccer and basketball.



Mariana Barbara, Dade County

I am an 18 year old high school student. My parents were told that I had an autism spectrum disorder when I was 4 years old. I was challenged by learning, communicating with people and coping with my environment. Since I learned differently, students and teachers viewed me differently and assumed that my diagnosis of autism would prevent me from achieving my goals. My parents were determined that I would not become a statistic. I had to attend endless hours of language therapy, occupational therapy and social skills groups.

My parents never told me that I had a disability when I was younger because they wanted me to have the same expectations as others. I have learned that I can endure hardships in order to complete my tasks no matter what disability I have. I have acquired a strong work ethic, proficient study skills and a powerful spirit. I want to tell the Governor that children with disabilities want to become taxpayers, get jobs, be independent but they need the support system to do so!



Michael Miller, Polk County

Michael was born 10 weeks early on May 3, 2002. He was in the NICU for 6 weeks. We were told he would catch up but very quickly he was diagnosed with mild Cerebral Palsy. Michael is developmentally delayed. He had few words and around the age of 3 had regressed to no words at all. He was diagnosed at age 4 with Autism Spectrum Disorder. Even though Michael does not have words to speak we work on communicating through pictures and a few signs. Michael loves to swing and climb on his swing set. His most favorite thing to do is swim and he has been learning to surf with the Surfers for Autism group here in Florida. Michael was added to the waiting list for the Home and Community Based Services waiver when he was 5 years old. He is now 10 and we are looking forward to the day that the waiting list is funded and he can benefit from community based supports.



APD Waiver Families

Nicholas Smith, Clay County

I have chosen to live at home with my parents because they are a little crazy and need me to keep them in line (just kidding they are nice people and I love them). I enjoy watching T.V. going to movies and any oldies music event that comes around.

Some people feel sorry for people that have cerebral palsy quadriplegia. I have been asked how I can continue to be happy when my body is such a wreck. I have told them that it's not a big deal. Yeah, I would like to walk and run and get into trouble but I am who I am. I'm just grateful to be alive, I am so blessed. I love everybody and I am loved very much. What more could a person ask for?



Christopher Sherman, Broward County

For all of my 46 years I've loved being out in the community with my family and friends. Generally, I am a happy-go-lucky guy. I have many friends throughout Broward County where I live. People who know me also say I have a great sense of humor because I smile often and laugh easily. I enjoy all kinds of music, from songs in church to rock and roll!

Thanks to those legislators who support programs that allow me to be healthy and safe and participate in the community, I have a wonderful quality of life. I wish everyone could have the same opportunities that I have, don't you?

Mary Houghland, Escambia County

My name is Mary Lynne Houghland and I am 32 years old. I live with my mom and dad. My two brothers have graduated college and moved into homes of their own. I like living at home. I have my own little apartment with all the special equipment that I need to keep me alive and safe. In addition, my mom takes loving care of me and puts up with me when I am in a bad mood. I do not have a voice box so I cannot yell or even talk but Mom can tell when I am mad.

When Mom works, a nurse takes over my care and ensures I get all my meds, feedings and monitors the ventilator so that I can breathe. I am lucky because I started to receive waiver services when I was young. That is why I have been able to stay at home. The waiver services

assist me to remain in the community where I want to be. I have a companion that takes me to do things in the community. She and I go to a nursing home on all the holidays and take goodies to the residents. They love to see me come. I am very thankful for the waiver and the services I have. I do worry about the 20,000+ individuals that are on the large waiting list for waiver services.



Connie Ivins, Pinellas County

Connie, my 57 year old sister, is developmentally delayed and brittle epileptic. She was a normal child and had encephalitis when she was twelve which destroyed the right side of her brain wiping out any memory or continued learning potential. At the age of twenty, she was involved in a car accident which caused her to have uncontrolled seizures. My parents passed away and Connie came to live with me 25 years ago.

I enrolled her on Medicaid which had little or no services available at that time. A Medicaid waiver became available a few years later and was our salvation in keeping our jobs. A nurse came daily to administer her medications and assist her daily living skills, through the Medicaid waiver. Physical therapy was provided to maintain her mobility. Without the Medicaid waiver and constant monitoring of her meds, Connie's seizures would have been life threatening and eventually Connie would have been institutionalized.



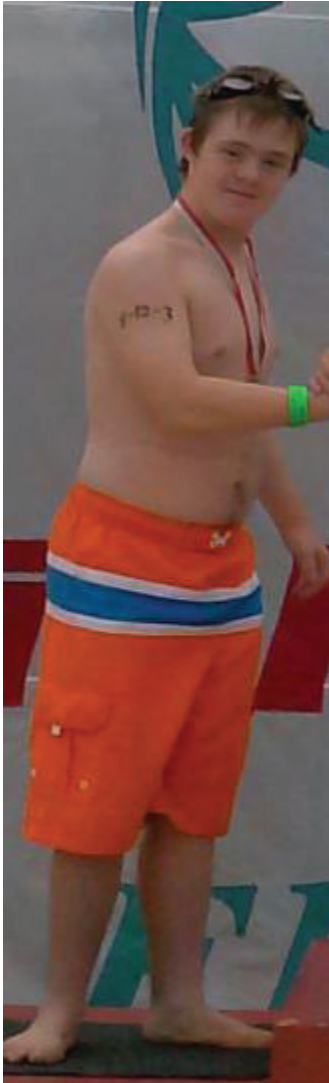
Jay Waffefeld, Broward County

I was born with a significant developmental disability 66 years ago. The doctors highly suggested to my parents that I should be institutionalized. My family believed that I could grow up and become a contributing member to society. I learned to overcome many obstacles from my family, friends, ARC, and APD.

I am fortunate to live in a group home that has allowed me to work, socialize, and attend culture and religious events. Others will tell you, I have a gift of loving life and being out in our community. I am retired now, but volunteer my time and skills along with my sister giving back to military veterans, elderly population, and other groups that really need a hand. Through the years, it was with the support and training of my family, friends, ARC, APD that I have been able to live in the community with respect and dignity.



Matthew Hearn, St. Lucie County



I either have an idea to chase or a song to sing. My motor doesn't stop very long. Life with Friends Chorus of the Treasure Coast and Special Olympics has provided me with training, self-control, and the opportunity to bloom in talents and abilities. In October 2013, I won the silver medal and in 2014 the gold medal at the Special Olympics' Summer State Games for the Aquatic Championship competition.

I learn best by moving and doing and being creative. Poor sleep and a bi-pap machine are my companions. I try to wake up to be cheerful and helpful, but emotional, verbal, and physical outbursts can take over like a tornado. I was offered waiver services to provide respite. My waiver support coordinator attends my IEP meetings. I receive Consumer Directed Care Plus (CDC+) waiver services that help me to have access to my community. Since coming on Medicaid, Applied Behavioral Analysis and assistant services have been of the most help. I also now have a mental health case manager who will advocate with the St. Lucie County Schools and offer therapy sessions to help me.

Over the years, Mom and Dad have worked tirelessly advocating for the rights of individuals with developmental disabilities. My mom talks to people in the same situation and tries to help them find what they need.

Job training is important to me because I want to be a construction worker to help in the city or county. I would like companion assistance, job coaches, and quality supported living options to help me to live and work in my community.

APD Waiver- Employed Customers

Gregory Lipps, Sarasota County

I moved to Sarasota in January 2004 from Port St. Lucie at age 31. This was a difficult change for me, but my mother helped me find a job at Peach's Restaurant as a dishwasher, and life was good. I feel important and successful at work, and they do not care if my reading or math skills are poor, or how I tell time. I'm still working about 10 to 15 hours per week and my boss, Cory, always tells me what a good job I am doing!



I am thankful for the home and community-based waiver services I have, because I learn new ways to take care of myself every day. I live in my community, but I know that some individuals are waiting for the same help that I receive every day, and I worry about what will happen to them and to me when my parents are not here.

Ruth Ogburn, Leon County

Ruth Ogburn is a very outgoing, cheerful 49 year old. She loves being independent with her own apartment. Ruth has worked at Wal-Mart more than 20 years. She graduated from Gretchen Everhart School, a special needs public school, in 1987. With the help of Vocational Rehabilitation, she got her first job a few months after graduation – a job she kept for 7 years before going to Wal-Mart. She lives in her own apartment (with some supports) and rides a special needs bus to work each day.



At an early age it was suggested by medical professionals that she be institutionalized. This was not done and time has proven that with supports she can be a productive member of society. The med-waiver program has provided these supports (along with her family) since she began working and moved into the community at age 23. She has now lived on her own for more than 25 years.

Laura Lynne Clements, Lake County

I am Laura Lynne and I have a lot of talents but I also have an intellectual disability that makes it hard for me to learn and remember how to do a lot of things that help me take care of myself and the things that I need to do every day.

A few years ago it became even harder for me to do everything. I needed a lot of help. My parents tried to help me but I was in a crisis that almost made me go into an institution to be safe and healthy. It scared me and scared my family who love me very much. We learned about the APD Medicaid waiver program. It was very hard, to be on the waitlist in crisis for 2 years. When I got on the waiver I was able to receive intense services, choose a small group home that I love, and behavioral services that really helped me. It took a long while but when I was ready, with the help of a support coach I now have a job at Target. I still need a lot of help as I have a lot of challenges but I love my life. I worry about losing services that help me, but also worry for others who need services, or who may lose their parents and not know what will happen to them because they are on the very long waitlist. I am on the iBudget and think it is good.

