Florida’s Family Care Councils

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Learning Objectives

- **Understand the role & functions of:**
  - Family Care Councils (FCC)
  - Family Care Council Florida (FCCF)

- **Recognize how FCCs provide resource information to family caregivers**

- **Appreciate how the role of FCCs evolved**

- **Describe how FCCs function as informal family support networks**
Initiated 20 yrs ago in statute - F.S. 393
Formalized system of family supports
Gave some feedback to local DD Program
Few families around state participated
No real involvement in decision-making
No information provided from Central office “experts” on plans, policies
Little expectation for families’ input
No funding support or education of families occurred
Evolution of the FCCs

- In October 2004 DD program split off from DCF and became Agency for Persons with Disabilities (APD)
- In 2000 FCCF became the statewide coordinating body for 15 FCCs (not statute)
- It was the vehicle for “meeting & sharing information” across Councils
- Initial statewide recognition of FCCF by APD, families & DD stakeholders was low
Florida becomes more involved with the HCBS DD Medicaid Waiver
- Individual service choices are required
- Care must really be “individual and family-centered”
- Professionals realized need to enter into partnership with families
- More federal $$ means more families requesting services (30k + 20K WL)
FCC Organizational Structure

- Independent from but advisory to APD
- 15 local councils & one FCCF
- FCCF membership comprised of Chairs of each FCC and officers
- Annual funding via APD budget for each FCC and FCCF (total $150,000)
- Funds to reimburse in-state travel, operating expenses, etc.
- Follow State of Florida financial policies
Purpose: Advise APD, plan for local family supports, monitor implementation & effectiveness of services/supports

Functions:
- Assist with information, outreach to families
- Recommendations for service implementation
- Advise APD on policy issues
- Meet, share information with other councils
Other Roles of FCC

- Liaison with community disability groups & coalitions (211, ESE, SNAC, UCEDD, FDDC)
- Outreach, info & support to Wait List families
- Identifying local support resources
- Participate in community fairs, expos
- Contribute, publicize APD resource directory
- Advocacy with local legislators
- Establish platforms on state policy issues
FCC Membership

- One Council in each of 15 DP (APD) Areas
- 10-15 governor-appointed volunteer members on each Council
- Three members must be DD consumers
- Other members: Parents, siblings, legal guardians (service providers excluded)
- Two, three-year terms; then one yr. hiatus
- Officers elected annually (Chair, Vice Chair, Secretary, Treasurer); Committees
Local FCC Meetings

- At least six times per yr; most meet monthly
- Minutes, votes recorded & approved
- Each Council’s by-laws determine quorum
- Large areas allow attendance via phone
- Advocates, community reps, service providers, support coordinators also attend
- and may be Associate (non-voting) Members
- Associates are actually community resources, may serve on committees
FCC Meeting Topics

- Service, advocacy issues in the local area
- Updates from APD area, regional offices
- Announcements from APD statewide
- Updates, issues & events from FCCF
- Annual Plan & Budget activity reports
- Reports from committee activities
- Educational/informational presentations
- Legislative priorities/positions
- Community announcements, events
APD recently consolidated into 6 regions, but FCCs were left in 15 local communities. FCCF Families involved across State system. Included in all Stakeholder meetings, calls. Policy decisions affecting families are now brought to FCCF before being finalized. Sit on various task forces; e.g., DD Council strategic planning for Wait List families. Input, opinions solicited by state legislators.
Example of Making an Impact

Family Care Council Florida (FCCF)
Interesting Floridians You Should Know
We are pleased to provide you with an inaugural copy of the booklet, “Interesting Florida Residents You Should Know.” It will provide you with a glimpse into the lives of some of your constituents who happen to have developmental disabilities. These profiles are being submitted by the Family Care Councils across the State to introduce you to our loved ones and to acknowledge the essential role that your support is playing in assuring their continued health, safety and community participation. Should you have any questions about the information you read here, please contact us at the above web site and we will be glad to reply.
“I’m Andrew, here’s my story!”

Andrew wants your support for:

Fully fund Florida’s Center for Autism and Related Disabilities budget – it has been reduced by 34% since 2010 resulting in reduced services while the number of newly diagnosed children with autism or related disabilities has increased.

Andrew Pappas is a happy twelve-year-old with a great sense of humor! He enjoys going to the same school as his younger brother and especially enjoys playing basketball after school with neighborhood friends. He has a moderate to severe hearing loss, hip dysplasia, and sensory integration challenges that deeply affect his daily living and learning skills and overall communication.

Andrew’s eligibility criteria for CARD services fell under the “related disabilities” category (cognitive delay & hearing loss among other challenges) – FAU CARD has been the most helpful organization in our community. Through their services Andrew’s team of teachers and care-takers have learned approaches for how to best teach him in the school, home, & community settings.

FAU CARD has always had a strong presence in our community – their staff collaborates with countless local organizations and is always prepared to provide assistance, communication, and education.

They are an invaluable team that reaches so many!

Andrew’s Accomplishments:

Andrew is learning to read, tell time, use money, he swims, plays basketball, golf & enjoys riding horses!

Andrew also enjoys competing in sports sponsored by Special Olympics.

He loves all types of music and relishes his classic guitar.

“My is a terrible thing to see and have no vision.”

- Helen Keller

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Personal:

- Wife of Christopher and mother of two wonderful boys: Andrew (12), Nicholas (8)
- South Florida resident since 1980; Miami-Dade, Broward, & Palm Beach counties
- Professional background: community association management & real estate sales

Affiliations:

- Family Care Council (Area 9), member/Chair
- Steering committee, past member/Chair (Agency for Persons with Disabilities, Area 9)
- Gold Coast Down Syndrome Organization, past board member
- Exceptional Student Education Advisory, board participation
- Elementary School SAC, member, past Co-Chair
- The School District of Palm Beach County, volunteer

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How FCCs Support families

- Problem-solving, referrals at meetings
- 1:1 mentoring; school/IEP advocacy
- Identify correct local APD resource
- Understand operation, changes in a service system constantly “in flux”
- Share community resources used by other members
- No longer alone – strength in numbers
- Important for both ends of age spectrum!