

Florida Developmental Disabilities Council, Inc.

FULL COUNCIL MEETING MINUTES- Day 2

Friday, September 20, 2024

Council Members Present: Elly Hagen; Eddie Hall; Dr. Dennis Hart; Yolanda Herrera; Dr. Jean Sherman; Carla Mercer; Lauren Modawell; Arizona Jenkins; Michael Sayih; Charlotte Temple; Christina Cordova; Caitlyn Clibbon; Dr. Beth Boone; Tremayne Simpkins for Victoria Gaitanis; Andrea Gary; Kira Houge; Susan Nipper / Anna Cleveland (for Taylor Hatch); Sarah Goldman; Denise Anderson; Austin Noll with Meagan Owens (for Kimberly Quinn); and Enrique Escallon (via Zoom)

Council Members Absent: Jennifer Duggar; Victoria Zepp; Kali Wilson; and Danielle McGill.

Staff Present: Valerie Breen, Executive Director; Dr. Sue Kabot; Kristin Vandagriff; Margaret Hooper; Monica Moye; Dr. Chris Reeve; and Jan Pearce

Hall called the meeting to order at 9:01 am.

I. Adoption of the Agenda

Noll introduced Owens as the new staff attending Council meetings for the Agency for Health Care Administration (AHCA).

Action Taken: Temple made a motion to adopt the agenda as presented. Goldman seconded. An opportunity for discussion was provided; none was offered. The motion passed unanimously.

II. New State Plan: Next Steps

- Hall introduced a presentation by Dr. Kabot and Jeff Feller, CEO of WellFlorida. Dr. Kabot provided background on the state plan development process.
- It was noted that DD Council members are to be the driving force behind the State Plan.
- It was also reported that collaboration with the DD Network and other partners is critical. This includes the two Florida University Centers of Excellence in Developmental Disabilities (UCEDD) and Disability Rights Florida (DRF).
- FDDC will be reaching out to stakeholders to obtain input on state needs.
- The state plan development process was noted to take 18 months.
- It was reported that information is being gathered about the State of Florida which includes demographics, state disability characteristics, as well as disability demographics related to residential settings.
- A portrait of state services will be developed looking at core areas established federally such as health, employment, housing, transportation, childcare, etc. This will become a report looking at present challenges in Florida.
- Dr. Kabot presented the requirements given federally by ACL that must be included within the state plan. The self-advocacy and leadership requirement was described. The Targeted Disparity requirement was denoted as well with examples provided from previous plans to relay context. The DD Network Planned Collaboration requirement

was discussed and defined to be work that is done with the Mailman Center, South Florida Center for Inclusive Communities, and Disability Rights Florida.

- It was denoted that task forces will need to look at their projects to determine what may need to continue into the next state plan.
- It was noted that the project grid with updates on efforts, per project, was included in Council meeting materials.
- Breen noted that sustainability considerations are integral throughout this process.
- Jenkins noted that the self-advocacy and leadership programs are good to have as they teach people with disabilities to stand up for themselves and others. Jenkins shared his experience being a Fellow and noted that our current program provider has really evolved the program and done a wonderful job.

Jeff Feller, CEO, of WellFlorida presented an overview of what the CRA process would include.

- An introduction to WellFlorida was provided. It was noted to be 1 of 11 health councils in Florida. Expertise includes program management, program evaluation, assessment of needs (county, regional, statewide, etc.). WellFlorida helped with the past FDDC CRA and has completed similar efforts for other entities. WellFlorida administers programs as well as provides lived experience administering social service programs.
- The role of the Council was discussed. Council members will participate in primary data collection such as focus groups and surveys. There will be a focus on self-advocates and family members/caregivers. Council members will participate in discussion of the analysis of the data as well. Council members were also noted to be driving the strategic planning discussion and selection of priorities. The goal was denoted to be developing a consensus in vision moving forward.
- The CRA and strategic plan development timeline was shared. The process began August 1, 2024. In July of 2026, the final plan will be submitted federally. Each phase was displayed on a chart denoting the timeframes for completion. Areas especially critical for Council member participation were highlighted.
- CRA data collection was discussed denoting the primary and secondary data which would be collected.
 - I. Phase 1 was noted to include a self-advocate survey, family member/caregiver survey, and focus groups with family members/caregivers and self-advocates.
 - II. Phase 2 will include focus groups with Council members, key informant interviews with Council staff, as well as state agency leaders.

With respect to secondary data, state information and the state profile will be created using existing data sets. State agencies will be contacted to obtain most data sets. Census data will also be utilized.

- The overall CRA analysis process was denoted. Focus on state issues and challenges will be supported by primary and secondary data which describe the status of:
 - I. Eligibility for services criteria
 - II. Analysis of barriers to full participation of unserved and underserved groups of individuals with developmental disabilities and their families
 - III. The availability of assistive technology, waiting lists, analysis on adequacy of current resources and projected availability of future resources to fund services
 - IV. Analysis of adequacy of health care and other services/supports/assistance that individuals with developmental disabilities received in facilities
 - V. The adequacy of home-and community-based services.

It was noted that focus groups will be slated for January 2025. Surveys were reported to be an opportunity for Council members to share the survey with those in their networks. It was clarified that even if a member is set for a focus group, they should also take the survey.

- It was reported that the state plan under development will run from 2027-2031.
- A development timeline was shared starting with the May 2025 Council meeting which will include introduction of the CRA findings.
- The September 2025 Council meeting will include votes on goals and objectives. Following this meeting, the 45-day public comment period will begin.
- The January 2026 Council meeting will include a presentation of public input as well as any suggested plan edits with a Council vote for approval. A second 45-day public input period may begin, if necessary.
- The May 2026 Council meeting was noted to include a presentation of public input, if necessary, and a final vote on the plan before it is submitted federally. Jenkins asked for clarification on how they would receive the survey. It was clarified that they will receive an email with a link that includes a blurb. The blurb denotes which link should be used, depending on being a self-advocate or family caregiver/family member. If there are survey questions, there will be a phone number to call.
- Modawell noted having many friends who are advocates for themselves and asked how to connect those who live in her intentional community to share their input. It was noted that she could share the survey link.
- Some focus groups will need participants who are not Council members so there may be opportunities to connect Council member networks with this opportunity in the future. It was clarified that the survey is an area for personal responses and focus groups can share personal and general issues holistically. Jenkins asked if interviews would be done over the phone, Zoom, or in-person. It was clarified that Council members will have a live focus

group in January 2025. WellFlorida will work with members on focus group participation and how they can connect their network with this opportunity.

VI. State & Sister Agency Reports

A. Agency for Persons with Disabilities (APD) Report

- Nipper reported on application eligibility to streamline the process and make it as transparent as possible with go live date set for fall. This will allow for submission and status to be conducted online. More information on the process will also be provided online.
- Care Navigation is now Hope Florida. It has been available since last summer. It supports serving complex cases served throughout multiple cases of care.
- APD can now offer care navigation services for voluntary participation. The goal is to create a seamless network of support for community living and achievement of goals.
- A CDC+ program update was provided. Support coordinators must inform participants of the CDC+ option. In collaboration with families, a CDC+ brochure is now available.
- 3,000 interest and offer letters were sent out to 3-5 pre-enrollment categories as well as three-six for those in managed care pilot areas.
- APD is working with ACHA and contracted managed care entity, Florida Community Care (FCC) to ensure enrollment is smooth. The first enrollment will be effective October 1st, with hundreds of responses delivered through mail.
- A caregiver age change occurred due to legislation; it has been lowered from 70 to 60 which allows for category 4 placement on the pre-enrollment list. Outreach has been conducted to identify category changes for over 200 clients. Additional changes continue to occur. The new application will capture this information.
- APD received funding to enroll individuals with a sibling in category 4-6.
- Florida Unique Abilities Partners program was established to recognize businesses that support the independence of those with a disability. This program will allow APD to build upon it.
- APD's Adult Pathways initiative is a partnership with AHCA and University of Miami-Mailman Center to develop a new Medicaid waiver program for those transitioning into adulthood. Three focus sessions along with regional meetings have been held to obtain input on program development. Key takeaways thus far are:
 - Safe place to live
 - Community support system and friends
 - A job
- APD is looking at enhancements in transition planning, working with sister agencies.
- Adult Day Training programs must be licensed by October 1st. The initial rule workshop has been held, and a second was held recently. Comments provided informed the draft rule language. ADT licenses will be for a 3-year period.

- Dr. Boone asked if people move from the pre-enrollment list onto managed care pilot, can people enroll in managed care if they are not in pre-enrollment? It was clarified they do need to be on the pre-enrollment list. It was asked what happens to previous pre-enrollment category spots once people agree to the managed care pilot should the pilot not work for them. Noll noted that sometimes plans work out well for individuals and sometimes they do not. It was shared that after a time of being on the Intellectual/Developmental Disability pilot, they are bumped up on pre-enrollment list and can move more quickly onto the iBudget waiver. If an individual didn't like the managed care pilot, a one-year timeframe is provided to move to a slot on either the long-term supports and services waiver or iBudget waiver. Breen noted that there are three ways to move off the managed care pilot: crisis, a year, and possibly a 6-month option with set criteria. This will be provided in follow up after the meeting. It was noted that if they move out of the managed care county, they will need to move onto a waiver. Breen denoted that once they enroll in the pilot, they have a full package of managed care.
- Temple asked about the amount of time this would occur.
- Nipper noted that the initial round of letters noted it focused on HCBS settings, not ICFs which go through annual choice options.
- Hooper asked about changes in the categories served by the pilot. Nipper clarified that crisis categories 1-2 would be included in the pilot.
- Dr. Sherman asked about the electronic system and improvements that have been made. It was noted that challenges have been present with iConnect, but progress has been made, with more provider reports generated. More information can be provided as follow up.
- Noll noted the commitment to find efficiencies, meeting with stakeholders to learn about challenges to improve the system.
- Clibbon asked how many letters were sent out total. 3,500 total letters were noted to be sent.
- Clibbon asked about what happens if they want to leave before a year. It was noted that follow-up will be provided after this meeting.
- Dr. Sherman asked about the situational assessment and if it was delivered on a regular basis every three years, noting updated assessments as people age is important. The QSI is the tool used and was reported to be completed every 3 years or more frequently if changes have occurred. Individual follow-up will occur after the meeting. Lapses in QSI assessments were noted to be something Dr. Sherman was hearing about.
- Herrera noted that iConnect glitches can make the support coordinators look inefficient and make communication challenging. She shared that the report is very valuable and asked for the report to be made available.
- Nipper offered concerns to be routed to her and she will support navigation to the appropriate state staff.

B. Agency for Health Care Administration (AHC) Report

- Noll denoted participating in Family Café and taking input from stakeholders back to inform his work.
- It was shared that the agency has been busy working with APD on the pilot program.
- It was noted that the managed care contract negotiations have concluded. Materials on changes coming and health plans for each region will be updated soon. A 2-page snapshot discusses expanded benefits. A longer slide deck (over 70 slides) covers all items in more depth. The first workshop on Veteran Administration services within managed care was held recently and resources on the changes for these services are posted online as well.
- The diabetic supply rule is being finalized and goes into effect Oct. 1. It will allow these supplies to be able to be picked up at the pharmacy.
- The home health aide program has been finalized regarding its rules and is effective October 1. It allows families to be reimbursed for services provided to children up to 8 hours a day, per child. Cordova noted confusion on the income parent/family caregivers can receive and asked if it was taxable and if it counted against family income that is looked at for obtaining services. Noll noted being in regular communication with the legislature about the bill to lessen confusion. The bill was designed to not exclude that income as countable income. It was noted that each family's dynamic and each program was different. Home health aide providers receive \$25/hour for these positions. A Department of Children and Family (DCF) style calculator would allow families to plug in their information and see impacts. Clibbon noted that for those that have concerns, stakeholders could reach out to Rep. Tremont regarding input should any amendments be offered in the future related to the bill. Concerns were noted regarding 8 hours vs. 12 hours. The floor for what agencies can pay was noted to be minimum wage. Herrera noted the critical nature of behavioral therapists and current shortages. Noll shared that his wife has a painful degenerative condition, and it allows him to bring lived experience as a caregiver to this work.

C. Department of Elder Affairs (DOEA) Report

- Houge reported that new federal regulations have come out and are being reviewed. The Older Americans Act is going to be reauthorized this year. The State of Florida is well aligned with the regulations. Most rules won't be implemented until 2028. Staff went to the HCBS Conference and co-presented with Director Breen. Senior Farmers Market and Nutrition Program provides seniors with local fresh produce. An event in Jacksonville was noted. Noll shared that he appreciated Breen supporting that presentation.

D. Division of Vocational Rehabilitation Report

- Simpkins reported that Gaitanis will soon be moving on from Vocational Rehabilitation. He shared that RSA monitoring occurred in February. The agency shift is moving towards closer alignment with federal regulations. The agency's paradigm shift is occurring with financial management system to support reporting to RSA. Many states are not fully using funding allotted, giving funding back federally. This can result in less funding, and possibly moving to order of selection. Aware, the new case management system, will

support fully using funding, including the 15% under WIOA for transition age youth. Focusing on employment outcomes like earning outcomes after exit at different intervals. The focus is on long term employment based on federal regulations. Speed of service from application/IPE start is in the process of being improved. Staff vacancies were a noted challenge. Times can vary based on region and staffing. Temple noted that the website having something for people to understand the VR process timeline and stressing applying before graduation would be useful. A brief FAQ was noted to be useful for the future. An orientation video was noted to be on the VR website which discusses timeframes.

E. Florida Department of Education- BEES Report

- Duggar was unable to attend

F. Department of Health, Children's Medical Services

- Gary reported on the background information on the agency. During the last council meeting, input was sought regarding desired items to be covered in these reports. Early Steps conducted a provider needs assessment to understand the primary drivers and hesitancy. Results were used to develop materials such as videos, flyers, etc. a career page has been created for providers. Efforts related to advocacy for additional funding were noted to be underway.
- It was reminded that services are provided where children live, learn, and play. Increasing the rate for early intervention services was requested.
- A study is being conducted of the program, in a surveillance model, to see what improvements can be made.
- Child find efforts were noted to be improving, with numbers of children identified and services being noted as having increased.
- Point of care marketing at pediatric offices has been initiated. Public service announcements have come out across social media to increase awareness to reach families and providers to bridge gaps
- The CMS health plan has transition assessment readiness beginning at the age of 14 and helps to identify needs and goals. This lessens the chances that gaps in medical care occur.
- A team of transition specialty care managers has been developed with specialty experience in disability and medical complexities.
- Title 5 program funded by HRSA is conducting a 5-year needs assessment.
- Enhanced self-advocacy skill building is occurring through webinars and a free for Florida residents annual summit (January 29-31, 2025).
- A roadmap was developed for providers to use to improve their ability to engage with people with disabilities and medical complexities.

G. University of Miami- Mailman Center Report

- Dr. Sherman reported on the background of the Mailman Center. A strategic planning process was noted to be ongoing. Three main priorities have been identified:
 - i. Develop/implement health equity training,

- ii. Further develop LEND curriculum, bringing it more up to date with technology and focusing on community partners looking at community participative research training in clinical services.
- iii. Using more innovative technology techniques within service delivery.

Training through Project SALT is ongoing, annually to biannually. The State of Nebraska sent Developmental Disability Council members to Project SALT to learn how to implement something similar in Nebraska. There will be an AUCD presentation discussing this at the next conference. It was noted that Project SALT was initiated through FDDC funds.

H. University of South Florida- Florida Center for Inclusive Communities (FCIC) Report

- Dr. Boone reported on some general information about UCEDDs and noted that they are part of a national network.
- ACL funding is slight but leveraged into obtaining other funding.
- FCIC has 28 programs and projects and has 16 million in grant funding. The focus is early childhood education, employment, community living, health work, and pre-service training.
- New grants have come in from United States Department of Education.
 - i. One is called STAY and focuses on cognitive behavior therapy to address chronic school absenteeism.
 - ii. The other is a 9.9 million award to integrate VR and Artificial Intelligence (AI) into Launch Services, focused on transition for youth with disabilities, including an array of employment services. It is a 5-year grant to support the use of those technologies.
- FCIC is also completing its 5-Year State Plan and is looking for ways to collect data together. Many questions and audiences are similar. FCIC's plan application is due in April. Family Café was utilized for the needs assessment.
- Three community conversations will be held in October across the state with virtual options available.
- Jenkins noted that Project SALT is a good program. He also shared that a training speaker noted that his disability was hereditary, when it was not. It was noted that more training might be helpful for trainers. This was noted to be 8 years ago, and that training has been modified and new presenters have been put in place including self-advocates who have been through the training and installed as presenters.

I. Disability Rights Florida (DRF) Report

- Clibbon reported on individual advocacy and legal representation for people with disabilities.
- DRF received a separate grant from the violence against women to improve how women are served in the state.
- A needs assessment is also underway with a findings report being forthcoming.
- A lawsuit occurred over incontinence supply coverage for adults, with the settlement being approved by the court and ACHA being presently engaged in rulemaking to adjust the rule.

- Regarding Supported Decision Making (SDM), the next steps were noted to be training entities regarding SDMA's and working with the state court administrator to train judges and attorneys.
- DRF is working with waiver support coordinators to train them as well. The DRF legislative agenda is in the process of being developed. The voting rights hotline was noted to be run through DRF and it was shared that if there are registration, vote by mail, or election day voting issues, people with disabilities can call the voting hotline to troubleshoot that issue.
- Dr. Sherman asked if DRF considers shelters available to women in local areas to be a place to provide technical assistance. It was noted that it is not at that phase yet but will be. Dr. Sherman denoted when looking at adequacy of shelters, to ensure the needs of older women are considered.

VII. Committee Reports

A. Public Policy Committee Report-provided by Sarah Goldman, Chair

Action Taken: Jenkins made a motion to adopt the report. Clibbon seconded. Discussion was offered; none occurred. The motion passed with one abstention- Gary.

B. State Plan Committee Report- provided by Dr Jean Sherman, Chair

Action Taken: Hart made a motion to adopt the report. Goldman seconded. Discussion was offered; none occurred. The motion passed unanimously.

C. Finance Committee Report- presented by Dr. Dennis Hart

Action Taken: Escallon made a motion to adopt the committee report. Temple seconded. Discussion was offered; none occurred. The motion passed with one abstention- Gary.

D. Executive Committee Report- provided by Eddie Hall

Action Taken: Hart made a motion to adopt the July 26 meeting minutes. Hererra seconded. Discussion was offered; none occurred. Escallon noted that Bylaws would not be tabled. All members voted in favor other than Gary who abstained. The motion was adopted and the minutes were approved.

Action Taken: Hagen made a motion to adopt the report. Jenkins seconded. Discussion was offered; none occurred. All members voted in favor other than Gary who abstained. The motion was carried.

VIII. Public Input

Hall asked if there was Public Comment, there was none.

The council meeting was adjourned at 1:17pm.