

Florida Developmental Disabilities Council

Full Council Meeting Minutes January 29, 2025-January 31, 2025 In Person

Council Members Present: Eddie Hall; Yolanda Herrera; Lauren Modawell; Enrique Escallon (via ZOOM); Michael Sayih; Charlotte Temple; Arizona Jenkins; Denise Anderson; Elly Hagen; Sarah Goldman; Danielle McGill; Carla Mercer; Kali Wilson; Susan Nipper (for Taylor Hatch); Caitlyn Clibbon (for Cherie Hall); Johana Valdivieso (for Kelly Rogers, Vocational Rehabilitation); Beth Boone, Jean Sherman.

Wednesday, January 29, 2025

Absent Council Members: Christina Cordova; Dennis Hart; Victoria Zepp; Kimberly Quinn; Patricia Bodiford; Kira Houge; Andrea Gary.

Guests: Danielle Towery, James Moore HR Solutions; Kerry Parsons, Nabor, Giblin and Nickerson; Amy Deaville, Information and Technical Assistance Center, Administration for Community Living.

Staff Present: Valerie Breen; Sue Kabot; Kristin Vandagriff; Margaret Hooper; Monica Moye; Chris Reeve; Jennifer Chung; Sarah Macaluso.

Hall called the meeting to order at 3:30pm.

I. Adopt the Agenda

Action Taken: Hagen made a motion to adopt the agenda as presented. Herrera seconded. Motion passed unanimously.

Hall noted that after the last Council meeting, he felt that members could all benefit from hearing the same information on important topics that the Council should be educated or re-educated on. Hall noted he asked Executive Director Breen to arrange presentations on Harassment, Florida Sunshine and Ethics, and our roles and responsibilities under the DD Act.

II. Anti-Harassment Presentation

Hall welcomed Danielle Towery from James Moore, HR Solutions who has served as the subject matter expert to the Council in all matters related to labor laws and personnel, and Kerry Parsons, attorney from Nabor, Giblin and Nickerson. Nabor, Giblin and Nickerson have served as the legal Council on all matters related to our public responsibilities and federal guideline requirements.

Ms. Towery provided background on the importance of understanding harassment relating to the workplace. Employee rights and responsibilities were covered. The importance of protecting FDDC's reputation was also noted. Examples were provided regarding what to avoid. Harassment related to protected classes were also denoted. Questions were posed to attendees to fully grasp protected characteristics under the law.

Escallon asked if there is anything particular to be aware of for Florida. Towery denoted that everything noted in the Power Point presented applied to Florida.

III. Florida Sunshine/Ethics Presentation

Parsons provided a refresher on Sunshine law, public records, conflict of interest, and ethics. The purpose of the Sunshine law was discussed and defined as protecting the public from “closed door” meetings. It was denoted that elected and appointed boards must abide by this law for both formal and informal gatherings of 2+ members of the same board regarding an issue that may come before them related to that board. Open publicly noticed meetings were noted with limited options where it doesn’t apply. Application beyond in-person communication was discussed such as telephonic, texts, emails, social media, etc.

Compliance to Sunshine law was discussed, including: 1) Reasonable Notice of Meetings, 2) Open to the Public, and 3) Minutes. It was noted that open public meeting exceptions include: 1) union negotiation for collective bargaining, 2) certain oral presentations given by competitors in a competitive solicitation process, and 3) discussions on pending litigation. Sunshine law violations were noted to be serious and could risk voiding Council decisions or recommendations

Public records law was discussed relating to the public’s right to have access to official business of any public body. Unless statutorily exempt and/or confidential, all records are subject to disclosure and must be retained pursuant to state records retention schedule. It was discussed not to use one’s position to secure a special privilege and should not disclose or use information not available to the public gained through their role for personal benefit.

If a conflict of interest arises, members were directed to abstain from any discussion, deliberation and/or vote regarding the matter. FDDC code of ethics was discussed. FDDC bylaws were discussed relating to Council governance covering board functions of day-to-day work as well as membership, duties, committees, and minimum meeting requirements.

IV. Questions/Answers

Escallon provided an example of how compliance might be broken for members. Escallon asked about ways to remediate or cure a violation. Parsons noted that the matter should be taken back to the board in an open public meeting and vote again to ensure it is cured and the violation no longer exists. Escallon asked related to bylaws about policy and procedures- how board and staff work on policy and procedures and what role was recommended. Parsons said that the board can look at policies and bylaws and that amendments can be made if ever needed. With respect to day-to-day policies, those are usually developed by staff and brought to the board for discussion and consideration.

Hooper noted that legislators can make laws exempting them from Sunshine law. It was noted that no federal laws run counter to this exemption. The legislature exempted themselves from Sunshine due to having their own ethics policies in place. Hooper noted that an organization’s bylaws dictate how people conduct themselves and asked if in the absence of state and federal law, if bylaws are still needed. Parsons noted that if it is in the bylaws, it must be followed, and it may have narrower rules than state and federal laws. Hagen asked if Sunshine law applies after the voting. Parsons said it would not apply after the voting unless the issue is likely to come back before the board again, however, it is not recommended.

Hall adjourned the meeting at 5:21p.m.

Thursday, January 30, 2025

Council Members Present: Eddie Hall; Yolanda Herrera; Lauren Modawell; Enrique Escallon; Michael Sayih; Charlotte Temple; Arizona Jenkins; Denise Anderson; Elly Hagen; Sarah Goldman; Danielle McGill; Carla Mercer; Kali Wilson; Kimberly Quinn; Susan Nipper; Caitlyn Cliboon; Johana Valdivieso; Beth Boone; Kira Houge, Jean Sherman.

Council Members Absent: Christina Cordova; Patricia Bodiford; Andrea Gary; Victoria Zepp; Dennis Hart.

Guests: Amy Deaville, Administrator Federal standards and requirements Information & Technical Assistance Center, Administration on Community Living.

Staff Present: Valerie Breen; Sue Kabot; Kristin Vandagriff; Margaret Hooper; Monica Moye; Chris Reeve; Sarah Macaluso; Jennifer Chung.

Roll call was conducted, and quorum was established. Hall called the meeting to order at 1:38p.m.

Hall welcomed everyone and asked Breen to introduce FDDC's newest staff person, Jennifer Chung. Breen announced the retirement of Jan Pearce, Director of Programs, effective January 31, 2025, and that Chung, along with Kabot and Reeve, would be fulfilling the projects Pearce oversaw.

I. Adoption of the Agenda

Action Taken: Escallon made a motion to adopt the agenda as presented. Jenkins seconded. The motion passed unanimously.

II. Approval of the September 2024 Full Council meeting minutes.

Action Taken: Jenkins made a motion to adopt the minutes as presented. Mercer seconded. Motion passed unanimously.

III. The DD Act and Council Responsibilities Presentation

Hall welcomed Amy Deaville. Hall stated that this presentation was to provide a better understanding of the DD Act related to roles and responsibilities for Council members and staff.

Deaville covered the following in her Power Point presentation:

- Council connections organization chart was shown to provide a visual representation of the national and state connections. It was noted that Florida is unique being the first nonprofit DD Council. Florida also is its own DSA, providing it independence.
- Federal DD Council creation through the DD Act was discussed. It was noted that the DD Act was still active and does not have to be reauthorized. It has been reauthorized once. The law could exist without funding which would be considered an unfunded mandate.
- The core functions of advocacy, systems change, and capacity building efforts were denoted.
- Federal hierarchy was discussed explaining the layers that include: Administration on Community Living; Administration on Disability, Office of Intellectual and Developmental Disability (OIDD). DD Councils are assigned to both program and fiscal officers within OIDD. Annual performance reports

and state plans are sent to and approved by OIDD. This information is then used for reports to Congress.

- Detailed description of what the Council is, was provided.
- DD Council must follow Federal and State laws, regulations, policies, and procedures. The state plan, budget, and staff hiring/supervision were highlighted.
- Council member roles, responsibilities, and conduct were detailed. Governance and management were defined.
- Roles were discussed within the context of members, staff, and the Executive Director. The basic duties of a Council member were provided as a list, with each highlighted with associated context shared. Deciding on a mission, hiring/evaluating ED, creating a 5-year plan and subsequently implementing and monitoring plan progress, approve the budget and monitor the spending of money. Mentorship and developing well-informed Council members was highlighted with strategies that can be implemented. ITACC recommends an annual survey regarding how they could participate better. Ensuring ethical integrity was a highlighted role denoting a mandatory conflict-of-interest policy. Improving the DD Council's public standing was discussed as being an important component of being a Council member.
- The concept of "responsibility to the whole" was discussed as it relates to Council members.
- Important duties for Council members such as attending meetings, engaging actively, and abiding by by-laws/policies/procedures.
- The DD Act references relating to Council staff was covered. It was highlighted that the Executive Director reports to the Council and the Council supervises the Executive Director. Council staff report to the Executive Director and the Executive Director supervises staff. The Council member and staff partnership in accomplishing the work of the Council was denoted. It was highlighted that Council staff should not go to Council members and complain about coworkers. There is an internal grievance policy that is to be followed. Guidance was given for Council members should this type of scenario occur deferring the staff person to the FDDC employee grievance policy.
- A chart was shared regarding basic tasks denoting activities and the Council member role vs. the Executive Director role.
- A Beyond Tokenism presentation was delivered supporting board inclusion through meaningful engagement. Six elements of successful board inclusion were shared. Members were encouraged to self-reflect and consider areas for future improvement.
 - Authentic membership
 - Deliberate communication
 - Full participation
 - Meaningful ways to contribute
 - True influence
 - Mentors and supports
- The importance of the 6 elements was denoted through the sharing of both individual outcomes and organizational outcomes. Increased self-confidence and expanded leadership roles were denoted as individual outcomes. Adoption of person-centered practices, increased quality and satisfaction, and expanded views of capabilities of people with disabilities were denoted as organizational outcomes.
- The ITACC website was highlighted, denoting a yellow button for Council member resources.

Escallon asked for a recommendation regarding funding percentage of usage for different categories. Deaville stated that the DD Act denoted 70% of the funds must be state plan activities and 30% of the funds can be spent on administrative. Hall noted that many people with disabilities have been seen as a token. He noted never wanting to be seen as a token, but as a person with integrity who worked hard, and contributed equally.

IV. Adoption of Recommendations from Standing Committees

Chair Hall noted that FDDC is conducting business differently for 2025 to ensure that all Council members have an in-person vote on key issues that come out of FDDC standing committees. It was reported that each committee will bring their recommendations for Council vote at our full Council meeting. This allows Council members who are not on committees or unable to attend committees to have their input into Council business at the full Council meeting. The process was denoted to include each chair sharing their committees' recommendations for full Council discussion and vote. It was also reported that FDDC will no longer be adopting committee reports.

A. Public Policy Committee Recommendations

1. FDDC staff to pursue educating federal and state legislators on the benefits of Medicaid and develop tools for Council members.

Action Taken: Jenkins made a motion to adopt the recommendation. Temple seconded. Motion passed unanimously.

2. Staff to pursue Medicaid redetermination, presumptive eligibility for I/DD population.

Action Taken: Jenkins made a motion to adopt the recommendation. Modawell seconded. Motion passed unanimously.

3. Adoption of a new annual advocacy award called the Bobbie Lake Family Member Advocacy and Leadership Award.

Action Taken: Wilson made a motion to adopt the recommendation. Temple seconded. Motion passed unanimously.

B. State Plan Committee Recommendations

1. The Council was provided with a total of 13 recommendations related to all 13 FDDC projects regarding their necessity in the next 5-year Council state plan. Escallon asked if this would include funding. Kabot noted that funding will be discussed at the September 2025 meeting.

Action Taken: Goldman made a motion to approve and accept the recommendations related to all 13 projects. Jenkins seconded. The motion passed unanimously.

C. Finance Committee Recommendations

1. Adopt the Budget vs. Actual presented by Thomas Howell Ferguson

Action Taken: Temple made a motion to accept the recommendation. Clibbon seconded. Motion passed unanimously.

D. Executive Committee Recommendations

1. FDDC to hire a Tallahassee based law firm, GrayRobinson, and their ethics attorney, George Levesque, to review that structure of FDDC and its bylaws, articles of incorporation and statutory requirements as a federally required entity, in Florida statute as a non-profit.

Action Taken: Temple made a motion to accept the recommendation. Clibbon seconded. Motion passed unanimously.

2. Adopt the recommended employee recognition program with an amendment that the employee receives the net amount of the award in their paycheck.

Action Taken: Escallon made a motion to accept the recommendation. Wilson seconded. Discussion was offered. Clarification was asked about the net amount of the full award. Breen clarified that what was provided in the Council packet was the employee recognition program noted that the award would go in their paycheck and would be taxed. The executive committee asked for the employee to get the full award. The program would be modified to include the committee recommendation. Motion passed unanimously.

3. Hire an outside consultant to conduct a salary and benefits study for FDDC.

Action Taken: Hagen made a motion to approve the recommendation. Sherman seconded. Motion passed unanimously.

4. Establish a Council Bylaws Review Task Force.

Action Taken: Temple made a motion to accept the recommendation. Escallon seconded. Motion passed unanimously.

5. Establish a Council Applicant Review Task Force to review current applications through the FDDC website for Council member seats.

Action Taken: Goldman made a motion to accept the recommendation. Clibbo seconded. Motion passed unanimously.

V. Chair/Vice Chair Report

Hall noted that the coming year may be a challenging one and it will be critical to stick together as a team to move things forward. His noted that his focus will be self-advocates and self-advocacy as it is key to everything the Council is trying to accomplish.

Vice Chair Escallon noted that they have both met with the Executive Director weekly and offered if there are concerns or questions, they are there and can address concerns with the committee. It was noted that members have many perspectives, and it is important to hear from every member.

VI. Executive Director Report

Breen's Power Point presentation was titled "Pivot for the Future". She stated that 2025 is a new year and we must pay attention to what the future may hold for DD Councils and those with I/DD. She stated that it is critical that we pay attention to what others are saying and look for paths for others to hear us. Breen recommended that Council members watch the Florida Channel and become engaged in the Florida legislative process since legislative session was about to begin.

Breen spoke to the desire to develop and lead Floridians with disabilities and their families in a collective commitment to sustain the Council's efforts long-term. Breen stressed the importance of everyone working together for the best of the organization and those with I/DD.

VII. Public Comment/Meeting Adjourned

There was no public comment.

Hall adjourned the meeting at 4:43 p.m. The meeting was adjourned at 4:43 p.m.

Friday, January 31, 2025

Council Members Present: Eddie Hall; Yolanda Herrera; Lauren Modawell; Enrique Escallon; Michael Sayih; Charlotte Temple; Arizona Jenkins; Denise Anderson; Elly Hagen; Sarah Goldman; Danielle McGill; Carla Mercer; Kali Wilson; Kimberly Quinn; Susan Nipper; Caitlyn Clibbon; Johana Valdivieso and Myrna Diaz; Beth Boone; Kira Houge; Andrea Gary; Jean Sherman.

Council Members Absent: Christina Cordova; Dennis Hart; Victoria Zepp; Patricia Bodiford.

Staff Present: Valerie Breen; Sue Kabot; Kristin Vandagriff; Margaret Hooper; Monica Moye; Chris Reeve; Sarah Macaluso; Jennifer Chung.

Guests: Secretary Shevaunn Harris, Department of Children and Families; Bridget Royster, Acting Assistant Secretary, Department of Children and Families.

Roll call was conducted and quorum established.

Hall called the meeting to order at 9:05 a.m.

I. Adoption of the Agenda

Action Taken: Escallon made a motion to approve the agenda. Mercer seconded. Motion passed unanimously.

II. State & Sister Agency Reports

Special guests were introduced from Dept. of Children and Families, Secretary Harris along with Bridget Royster, Acting Assistant Secretary. Breen noted that she will pursue approval to add a Department of Children and Families seat to be represented on the FDDC Council.

Department of Children and Families (DCF)

Secretary Harris noted that there was a significant pause in Medicaid redetermination due to the pandemic. In late 2022, Congress instructed states to resume Medicaid redeterminations. There were 12 months to complete redeterminations, making 13 contacts each before disenrolling. The I/DD population was at the end of the redetermination process. She noted they were working with the Agency for Persons with Disabilities (APD) and sharing files to be able to alert support coordinators. Notification was made before termination to try to ensure individuals were not disenrolled unnecessarily. It was identified that agency changes regarding uploading forms, etc. needed change. Additional education was determined to be needed around the process.

It was noted that there were a lot of people on Supplemental Security Income (SSI) with changes in income that meant SSI was terminated and individuals didn't realize they needed to come to DCF to obtain their Medicaid as that was linked to their SSI. She reported that DCF desires to make the process smoother and lessen the amount of documentation that needs to be submitted. They have put a pause on disenrollments to assure that they can get the "fixes" and education completed.

Harris reported that the federal government provided additional information in November allowing tapping into 3rd party information. If DCF can validate that finances haven't changed, then they won't send a letter and will re-enroll the individual in Medicaid. Significant streamlining should be noted in February 2025. The SSI process will continue to be refined and DCF wants to continue to work with FDDC on stakeholder input processes. DCF wants to ensure that individuals maintain needed benefits and wants to do all they can to support process enhancement. They noted being open to input and wanting to collaborate to make the process better.

Hall opened the floor for questions.

- Goldman suggested having a checklist for those on SSI Medicaid and moving to DCF Medicaid. Challenges with classification in DCF system for those using Working Peoples Program were noted. Secretary Harris noted that they are working to get all financial information and a waiver indicator, working with Agency for Health Care Administration (AHCA). This will enable them to see that the individual is an iBudget client.
- Jenkins noted being one of the individuals who was discontinued. He thanked DCF staff for being present and listening to the input. He noted the issue regarding how long it takes to re-apply and get a case manager. The process was noted to be long, 30-40 days until a case manager can look over everything. He noted he had good caregivers who are flexible, but without payment caregivers will stop working. He noted that both the timeframe and delays were important to resolve. Harris noted that the new process should be more streamlined from a timeline perspective. There is a specialized team now that can look at these cases with an updated escalation process.
- McGill asked if there is a phone number for the specialized team for the escalation process. It was noted that she has received calls from families that the forms are hard to understand and do not know what needs to be collected. It was noted that a checklist would likely be very helpful. She noted that the process is a lot of work which is very hard for this population.
- Sherman shared her situation with her son as his legal guardian advocate. She stated that she never received a Medicaid notice. She also noted having dental insurance through Medicaid that was assigned to her son, but does not cover sedation dentistry, which he requires.

- Temple noted that she's talked to a lot of families with many different scenarios. She said that 50-60% of them don't know what benefits they have. They don't always know what they need to establish themselves with Medicaid for the waiver through a process outside of SSI. In the past the only way to get past the online system was to do a new application which then triggers a new eligibility process.
- Clibbon noted that she is hearing from clients that there are long wait times and being told they need to keep submitting additional information, prolonging the process. She reported that DCF workers are often not aware of programs like Working People with Disabilities program. Harris said they would be interested in collaborative training.
- Hooper noted appreciating DCF staff time and noted that the Council has taken a position to recommend an ex parte process to protect individuals against disenrollment while the process of submitting documentation was undertaken.
- Breen noted a comprehensive checklist seemed to be a common request from Council members. She offered, on behalf of the Council, to facilitate meetings to develop such a tool.

Agency for Persons with Disabilities (APD)

Nipper noted that regarding the Medicaid re-determination process, APD has been working collaboratively with agencies and passing on information that is needed. Lists have been going to DCF from APD on a regular basis. Information had been shared proactively for 12 months to provide waiver support coordinators with advanced information to allow for planning. Nipper reported that APD is working with DCF for waiver support coordinator training. This will cover MyAccess and the portal as well as the document submission process. APD is setting up dedicated teams to work with DCF partners to ensure questions and escalation issues are handled. APD will host virtual and in-person events to address issues as they come up.

Nipper reported that APD is excited to announce the online application portal. They have received hundreds of applications thus far. Individuals can now create an account, upload documents, and can view their status. There's a quick guide available to ensure that they know what is needed to begin the process.

The Florida Unique Abilities Program recognizes employers who hire people with disabilities. Toolkits for job seekers and job providers have been created.

APD has sent out interest letters for waiver enrollment and the managed care pilot. Nipper reported that 166 people were enrolled in the iBudget waiver; 306 in managed care pilot. Four hundred (400) regional events were hosted to support enrollment.

Nipper reported that the request for proposal (RFP) for dental closed on 1/29/2025 and they will be looking at submission eligibility and then review the proposals. Funding that APD received from the legislature can cover preventive and medically necessary dental care for APD clients until the program is online.

Agency for Health Care Administration (AHCA)

Quinn reported that the Statewide Medicaid Managed Care (SMMC) program is set to go live February 1, 2025. She reported that one of the changes was the opt out vs. opt in facet. iBudget enrollees are voluntary for managed care for regular medical. They can be in managed care plans or use the fee for service care system. If no action is taken, people are automatically enrolled into a managed care plan.

They can opt out at any time as it's a rolling open enrollment period. Some system updates have occurred and opt outs are processed daily. There are some benefits in managed care not available for fee for service such as: over the counter stipends, equine therapy, swimming lessons, etc. The opt out phone number was provided, 877-711-3662. If opting out isn't seen the next day via the AHCA portal, individuals were directed to call the helpline at: 877-254-1055. If anyone has issues, Quinn noted she'd be giving her card and offering to assist with the process. She said that ACHA's desire is that this would be a seamless process.

Hagen noted feedback from individuals and families regarding confusion on the letter received on opting out. She noted filling out the form and not hearing back. She called and was told to send a guardianship document. Nothing in the portal noted a change. She was then told she needed additional information. She checked again and noted they had not received it. It was suggested that individuals receive an email on what is required.

Escallon noted that this happened to him as well and it is a systematic problem. He noted having full guardianship of his son and that for those who are low incidence or need specialty medical care, working with specialists who are known to them may be critical.

Wilson noted that many families are likely to have issues starting February 1st. She stated that the impact of the re-determination resulting in the loss of Medicaid for the I/DD population combined with limited-service providers is a huge problem. When billing opportunities go away, smaller organizations really struggle. One smaller Arc hasn't been paid for months. Every change has a big impact.

Quinn noted that if anyone is moving into managed care, there are continuity of care requirements. The managed care plan must provide the same level of services. They have 90 days to get the individual with a commensurate provider. They can sometimes enroll the individual's provider in their network or find another provider that is in their network. There should be no disruption in services due to enrolling in managed care.

Breen requested that the communications departments in DCF, APD and AHCA include Breen in their e-mail correspondence so she can share with the Council pertinent information that would help inform the I/DD population.

Department of Elder Affairs (DOEA)

Houge noted that she did not have any significant updates and deferred her time to another speaker.

Department of Education- Vocational Rehabilitation (VR)

Diaz reported that supported employment included supporting those currently making subminimum wage. The percentage of individuals who exited Vocational Rehabilitation in competitive integrated employment was 41.4% which is an increase from past years. VR is continuing to build their capacity to deliver Discover and customized employment.

Valdivieso noted that VR has a new Director, Kelly Rogers. She stated VR's top priority is the speed of service delivery. The average time from application to receiving services has been reduced. They are working to further reduce this process timeframe. It was noted that 43 active Project SEARCH sites are supported and a few more will open in August 2025. Two hundred ninety-three (293) interns graduated from Project SEARCH with 161 having achieved competitive integrated employment.

Department of Education- BEES

No one available to provide a report.

Department of Health, Children Medical Services

Gary noted that she did not have any critical update and deferred her time to another speaker.

University of Miami- Mailman Center

Sherman noted the next Project SALT class starts in February 2025 and recognized Council member Michael Sayih as being a new participant in the February class. Sherman noted that the program is now being used in Nebraska. Sherman deferred the rest of her time to other speakers.

University of South Florida- Florida Center for Inclusive Communities

Boone thanked everyone who filled out the needs assessment. The needs assessment was finished, and the grant will be submitted soon.

Disability Rights Florida

Clibbon noted they are hiring their new Executive Director.

III. Public Comment

There was no public comment.

Hall adjourned the meeting at 10:31 a.m.