

**LOUISIANA DEVELOPMENTAL DISABILITIES COUNCIL**  
**October 18, 2007**  
**MEETING**

8:30 A.M.

Holiday Inn South  
Baton Rouge, Louisiana

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1. GREETINGS AND INTRODUCTIONS

- A. Lynette Fontenot, Chairperson of the Council, welcomed everyone to the meeting. She stated that Sam Beech will assist her with the meeting since Donna Breaux is not in attendance. Ms. Fontenot stated there are forms on the table for anyone who would like to address the Council. Time is allowed at the end of the meeting for people to speak for five minutes each. Ms. Fontenot reminded those present that Council Bylaws do not allow for proxy voting; anyone representing a Council member cannot vote on any issue.

B. MEMBERS PRESENT

Jeanne Abadie  
Jared Armstrong  
Sam Beech  
Sharon Dufrene  
Melissa Fayard  
Lynette Fontenot  
Rocky Fusilier  
Trudye Jones  
Billie Ruth Kvaternik  
Kay Marcel  
Willie Martin  
Ida Mialaret  
Johnnie Morris  
Jerry Phillips, BHSF  
Lois Simpson, AC  
Godfrey White, GOEA  
Phil Wilson, HDC

C. MEMBERS ABSENT

Susan Berry, OPH  
Donna Breaux  
Robin King  
Kathy Kliebert, OCDD  
Shelia Madison  
Nanette Olivier, DOE  
William Payne, OMH  
Matt Rovira, GODA  
Debbie Schilling  
Marian Vigo  
James Wallace, LRS

D. STAFF PRESENT

Shawn Fleming  
Paige Freeman  
Robbie Gray  
Kevin Hill  
Kandi Smith  
Sandee Winchell

E. GUESTS IN ATTENDANCE

Anna Brown - Guest of Johnnie Morris  
 BJ Chism - FHF of NWLA  
 Mary Jacob - FHF of GNO  
 Karen Scallan - FHF of Louisiana  
 Gracie Haggard  
 Elizabeth Gary – NFHF  
 Belinda Grand – Guest of Billie Ruth Kvaternik  
 Dora Chandler - Guest of Lynette Fontenot  
 Betsy Snider for Susan Berry - OPH  
 Brenda Martin – Guest of Trudye Jones  
 Sheryl Doga - Guest of Lynette Fontenot  
 Barbara Fayard – Guest of Melissa Fayard  
 Nora McKenzie – FHF of Greater Baton Rouge  
 Tessie Blanchard – Catholic Charities of Baton Rouge  
 Carol Calix – FHF of SELA  
 Robert Levy - OMH  
 Roseland Starks - LRS

2. MINUTES OF APRIL MEETING

Ms. Fontenot entertained a motion to accept the Minutes from the July meeting.

Motion Passed - Moved to accept minutes. Kay Marcel. Seconded by Willie Martin.

3. CHAIRPERSON’S REPORT – Lynette Fontenot.

Lynette Fontenot discussed the meetings and activities she has been involved in since the July meeting:

- **Meeting with Dr. Cerise and Staff**

On August 23, Sandee Winchell, Phil Wilson, Lois Simpson, and Ms. Fontenot met with Dr. Cerise and members of his staff. Ms. Winchell began the meeting by asking about the status of the Developmental Centers. Metropolitan Developmental Center only has 16 persons (residents). All residents will be relocated by October 15<sup>th</sup> and all but two are going to community homes. The property will be turned over to the Division of Administration in January for leasing and after January will be rented at fair market value.

The target date for all Columbia residents to move off campus is the end of the fiscal year.

Leesville residents only stay at that facility for a total of six to eighteen months so it is not feasible to move these services into the community at this time. OCDD still plans to close Leesville according to their five year plan by developing therapeutic foster homes as an alternative.

Dr. Wilson asked about the sheltered workshops and the supports waiver. Kathy Kliebert indicated that the supports waiver does provide financial incentive to providers for supported employment over sheltered workshops. OCDD has developed an employment plan and is getting technical assistance from the Supported Employment Leadership Network. Ms. Winchell and Ms. Fontenot asked about the status of using data from individual assessments to prioritize the waiting list and the allocation of waiver slots. Ms. Kliebert provided a schedule of how waiver slots would be filled throughout the year and an outline of completed and anticipated components of Louisiana's assessment and resource allocation project. Ms. Kliebert also provided a timeline for implementation of the Money Follows the Person Grant.

Ms. Simpson asked about the status of mental health services for the Greater New Orleans area and DHH provided an update on the number of beds that would be opening in the near future.

There was also a discussion concerning the DSP Wage Study called for in House Study Resolution 10.

- **Ad Hoc Committee for Inclusive Schools Art Contest**

On August 23, Robbie Gray reported that the entry information had been sent out. The Ad Hoc Committee met and discussed the judging of the entries. The judging is being held at the State Library the week of October 12-19, 2007. Ms. Fontenot encouraged DD Council members to go by and judge the entries.

The Art Demonstration will be held November 3<sup>rd</sup> at Cortana Mall from 10:00 a.m. to 4:00 p.m. Ms. Fontenot hopes to see some of the Council members there.

On December 5<sup>th</sup>, the Arts Contest Awards Ceremony will be held at the Claiborne Building from 2:00 to 4:30 pm.

There was a conference call on October 11<sup>th</sup> to finalize the details of the contest and awards ceremony. There were no changes made.

- **Executive Committee Meeting**

The Executive Committee Meeting was held on August 27<sup>th</sup>. The purpose of this meeting was to discuss the additional funds available which were underestimated at the April planning meeting. The committee approved \$10,960 to be used for computer equipment, software, conference room chairs and miscellaneous operating expenses. That left funding for new contract activities. If Congress is able to pass legislation to increase appropriations for DD Councils, the council should receive \$91,000. Ms. Winchell and Shawn Fleming recommended that \$9,100 be held for operating costs and still have \$81,900 for new projects. The Committee discussed ways to inform members of the council about the funds and get input from members to be presented at the Committee of the Whole.

The next item of discussion was one of the Council's contractors. Ms. Winchell shared letters of complaint that had been received regarding one of the Council's contractors and the response to the first of these letters. She also shared two emails from the contractor and her response to them. The committee decided to send a letter to the contractor to address this issue. If members would like more information regarding these issues, please contact Ms. Fontenot.

Ms. Fontenot took the time to remind all Council members of the Council's protocol for handling concerns or complaints. If anyone calls or approaches a Council member with a concern or complaint about an organization, project or program funded by the Council, that Council member has an obligation to take the concern directly to the Council's Executive Director or to direct the individual with the concern to write a letter to the Council's Executive Director. Ms. Winchell will then determine if the complaint needs to go to the Executive Committee, if staff will investigate, or if the Council has another mechanism to investigate the complaint.

On August 8<sup>th</sup>, Ms. Winchell asked the Executive Committee for clarification on the Council's contract requirement for Families Helping Families' Executive Directors to be the parent of an individual with a disability. The Executive Committee decided that the requirement should be a developmental disability but that existing Executive Directors not meeting this requirement would be grandfathered in. On August 10<sup>th</sup>, Ms. Winchell requested that the committee wait and allow the issue to go before the full Council for a vote because she learned it was going to be a controversial issue. Ms. Winchell then invited Families Helping Families of Louisiana to submit a recommendation to the Council regarding this requirement. Council members should have received the FHF recommendations during their committee meeting. The Executive Committee again discussed this issue at Wednesday's meeting and decided to recommend that the Families Helping Families Directors must be the parent, family member, or direct caregiver of an individual with a developmental disability or a person with a developmental disability and someone who has extensive personal knowledge and experience in disability issues. Current Executive Directors not meeting this criterion would be grandfathered in.

In addition, the Council would develop a formal mechanism whereby the FHF centers would be able to seek a waiver from the Council to allow an applicant who is qualified and experienced in the field of disability issues, advocacy for individuals with disabilities, and/or non-profit management. Individuals seeking this waiver need not meet the developmental disability requirement above but must be a parent, family member, or direct caregiver of an individual with a disability, or a person with a disability.

The Council would also develop a form for the FHF Executive Director and Board President to complete stating that the Executive Director meets the developmental disability requirement and specifies the documentation the board has on file that documents the disability – for example, an IEP, eligibility for OCDD, etc. This form will be signed by the Executive Director and Board President.

This recommendation will be discussed and voted on during new business.

The Committee approved a line item transfer of \$6,011 in state funds from salaries to contracts that had been appropriated to the Council by the state. The Committee is recommending these funds be amended into the INCS-Northwest supported living contract to pay for DSP pay increases and other needs.

The Committee discussed ideas for the Council’s legislative agenda that were generated at the last meeting and is recommending five items for the Council’s consideration during new business: funding for 3000 waiver slots, the message to align resources with demand, housing legislation, transportation legislation, and the creation of a youth transition core team.

Council Member travel stipends were discussed at the last Council meeting. To date, the Executive Committee has awarded \$271 to Willie Martin and \$430 to Trudye Jones. This leaves a balance of \$2,299 in the stipend fund. This morning the Committee approved a stipend request for \$336 for Sharon Dufrene to attend the Louisiana State Autism Conference and a workshop on Asperger’s Syndrome. That leaves a balance of \$1,963 in the Council’s stipend fund.

- **Gracie’s Retirement Party**

On September 21, Ms. Fontenot attended Gracie Haggard’s retirement party. She stated what a great job Ms. Winchell and the staff did preparing for the party. Ms. Fontenot also had the opportunity to meet Paige Freeman who replaced Gracie Haggard.

- **Representative LaFleur's Rally**

Ms. Fontenot was invited to attend a rally for Representative Eric LaFleur on September 23<sup>rd</sup> for his bid for Senator. Representative LaFleur was on the Appropriations Committee and strongly supported the Council's efforts to get more support services and waiver slots. Ms. Fontenot was introduced as Chairperson of the Council and was able to tell a large group of people about herself and the Council. Representative LaFleur stated that if he was elected Senator that he would continue to work with the Council.

Bernard Labas will be taking Senator LaFleur's seat as a representative because he does not have any opposition. He is a family friend of Ms. Fontenot's and when he heard of the Council and its work, he stated the Council could call on him anytime.

- **Planning Ad Hoc Committee Meeting**

On October 1<sup>st</sup> Ms. Fontenot attended the Planning Ad Hoc Committee meeting to discuss the use of funds which were not allocated at the April meeting. This was discussed at Wednesday's meeting of the Committee of the Whole.

- **NACDD Conference in San Diego**

The National Association of Councils on Developmental Disabilities annual conference was held on October 8<sup>th</sup> and 9<sup>th</sup>. It was attended by Ms. Fontenot, Ms. Winchell, and Dora Chandler. The keynote speaker on Monday was Dale DiLeo, author of *Raymond's Room* and a disability consultant and advocate from Florida. His topic was "The Future of Inclusion is Now." His book describes Raymond's room as being a room which was used to lock away young men with Autism. He stated that although this room may no longer exist, in reality people with disabilities are still being locked away from the rest of society. He also talked about obstacles such as labeling, grouping, and segregation which we still face today as we strive to be included in our communities. This session was very informative and interesting.

Ms. Fontenot, Ms. Winchell, and Ms. Chandler attended several concurrent sessions. These sessions were about powering advocacy through community organizing and advocacy for person-centered leadership. Another informative session was about an innovative model to close state developmental centers and develop individualized community support.

During the awards luncheon, Karen Flipppo was recognized for her years of service as CEO of the National Association of DD Councils. She is retiring, so this was her last meeting.

On Tuesday, speakers presented on the topic of emergency preparedness and how this impacts individuals with developmental disabilities.

Another session Ms. Winchell and Ms. Fontenot both attended was about supporting lives, building careers, and best practices for collaborative partnerships. The speaker shared how twenty-six states are using the curriculum of the College of Direct Support to increase workforce development. This curriculum can be easily accessed online.

Overall, the sessions were informative. Ms. Fontenot stated her appreciation for being able to attend this conference.

#### 4. EXECUTIVE DIRECTOR'S REPORT - Sandee Winchell

Ms. Winchell discussed the following:

- **New Council Members and Staff**

Sandee Winchell welcomed Rocky Fusilier and Melissa Fayard and recognized them as the most recently appointed Council Members. Ms. Winchell also acknowledged and welcomed Heather Mobley, Lynn Cannon, Roseland Starks and Simone Honore-Cretien whose Council appointments are pending in the Governor's Office. Ms. Winchell stated she is optimistic these appointments will come quickly. She also welcomed Paige Freeman to the DD Council staff. She also welcomed Gracie Haggard and expressed her appreciation for Ms. Haggard being here today and assisting Ms. Freeman with her first Council Meeting.

- **Advocacy**

Ms. Winchell has continued to advocate for 3000 vouchers for rental subsidiaries for permanent supportive housing units. She sent individualized emails and letters to every member of Louisiana's Congressional delegation and sent a request to LaCAN and FHF directors asking them to do the same. There has not been any indication as to whether Congress will appropriate these funds or not.

- **Waiver Services**

Ms. Winchell also continues to advocate for the reinstatement of waiver services for people during in-patient hospital stays. This would allow people to maintain their PCA services during their hospital stay. This service was once available to individuals in Louisiana until CMS indicated that it had to be discontinued. Ms. Winchell brought this to the National DD Council organization to have advocates on the federal level ask CMS to change the regulations. While researching the policies it was discovered that having waiver services during in-patient stays was not a CMS prohibition. Ms. Winchell received the regulation and shared it with Jerry Phillips and Kathy Kliebert who are pursuing this issue with CMS. While making these changes is a very slow process, efforts continue to get the services re-instated.

- **National Association of Councils on Developmental Disabilities (NACDD)**  
NACDD's Legislative priorities for the year are as follows:
  - Priority 1:** Leading the Way – takes the most action on issues and included in that priority are DD Council appropriations and reauthorization of the DD Act.
  - Priority 2:** Lending Support – works closely with disability partners and coalitions including the main ones which are mental health parity, the Community Choice Act, a bill dealing with direct support professionals, Lifespan Respite and other education and employment programs.
  - Priority 3:** Keeping Track/Monitoring Bills Closely – some Autism bills are included in the bills being monitored.
- **National NACDD Conference in San Diego**  
Ms. Winchell stated the entire conference was informative and energizing. One particularly enlightening bit of information was that the State of California has an entitlement act for services that dates back to 1969. It's called the Lanterman Act and everyone with a disability has an entitlement to services. There is no cap on services, no waiting list and everyone gets community services to the extent that they need. A combination of waiver services and state funded services are used. It was reported that people with disabilities have moved to California to get services. During the 1980's the state was having budget deficits and tried to cap services, but someone filed suit. The state supreme court ruled that the state could not cap services because the bill was an entitlement act. The state has an obligation to pay for what people need to live independent, productive lives in the community. There are over 300,000 people in California being served. It takes approximately three months to process new applicants, and the DD Council of California wants to shorten the length of that process.
- **Master Copy of Council Member Address List and Disability Groups**  
Ms. Winchell distributed the master list of Council Member Addresses and Disability Group memberships for members to make any necessary updates and for new members to add their information.
- **Orientation**  
Orientation will be during the January meeting. It will begin the evening of the 15<sup>th</sup> and end at noon on the 16<sup>th</sup>. Veteran council members will be called upon to play a role in orientation.



- **Legislative Candidates Survey**

The Legislative Candidates Survey results have been posted on the Council's website. Ms. Winchell thanked the staff for working very hard on this initiative. It was a huge undertaking with about 400 candidates running for the Legislature. Council members were encouraged to continue making visits to the candidates. She indicated that Council members will have an opportunity to report on their candidate visits later during the meeting.

Council members were given the opportunity to ask questions concerning the Executive Director's report mailed out prior to the meeting.

## 5. BUDGET REPORT – Shawn Fleming

Shawn Fleming discussed the budget report included in the Council members' packet.

Two budgets were shared. A final year budget from State Fiscal Year 2007 was shared so Council members could see the final amounts that were spent across categories. Mr. Fleming indicated that the expenditure balances reflect that the vast majority of funds allocated to the Council were used last year.

The August 2007 expenditure balance has the distribution of Council funds across the various categories. Mr. Fleming indicated that the budgeted amount for contracts will be adjusted in December to reflect the funding decisions of the Council. It is anticipated that another adjustment will be in the salary category with any additional funds going into contracts. One contractor agreed to work with the Council in the timing of the delivery of services to balance the adjustments across the state fiscal years. Since there will be additional staff leaving and being replaced, staff will have to wait until December or January to know the exact amounts that need to be adjusted in the salary category.

The Executive Committee did allow for an increase in funds to upgrade and/or replace aging computers and furniture in the office. Mr. Fleming expressed his appreciation for this decision.

## 6. COMMITTEE REPORTS

### A. COMMITTEE OF THE WHOLE – Kay Marcel

Kay Marcel stated the Committee of the Whole met to consider recommendation from the Planning Ad Hoc Committee. The Committee of the Whole did approve and will be recommending under new business that the following projects receive:

- Louisiana Youth Leadership Forum to be held in July 2008 receive \$17,500.
- The Partners Reunion to be scheduled between July and September 2008 receive \$16,000.
- Innovations and Education Child Care Training project receive an additional \$20,000 to allow for full implementation of the original project.
- Additional funding to three Families Helping Families Centers to provide additional stipend funds as follows:
  - FHF Acadiana receive \$3,400
  - FHF of GBR receive \$4,986
  - FHF of Northwest La receive \$2,623.

This will be voted on by the council when voting on Committee recommendations.

## B. HEALTH/EDUCATION/EMPLOYMENT – Sam Beech

Sam Beech discussed the Health/Education/Employment Committee as follows:

- Internship Program – Kandi Smith stated four young adults had completed the training of the Government Intern Training Project. Graham Calderera has been hired by Senator Butch Gautreaux’s office. It is hoped that these efforts can be expanded to include another region where another intern can be hired through a governmental office.
- School Art Contest – The school art contest received over 160 entries. Ms. Beech encouraged the Council members who have not judged to go by the State Library on Fourth Street to judge the entries. Ms. Beech stated that the library hours are from 8 – 5 so they need to be there by 4 to give themselves adequate time to judge. The contest ends today, but Ms. Gray will leave the display up until Friday at noon to give those who have not judged an opportunity to do so.
- New Members- The committee spoke to the new Council members and explained to them some of their roles and responsibilities on the council. The new members were informed that it is expected that they would not know or understand all of the Council’s actions in the beginning, but they will eventually understand what is going on and where the Council is going with its actions.

## C. SELF DETERMINATION/COMMUNITY INCLUSION/HOUSING – Kay Marcel

Kay Marcel discussed the Committee actions:

- People First – Becky Zito reported to the committee that People First was working hard and has re-established two Chapters. One chapter is in Jefferson and another is on a college campus at LSU-Eunice. Both of the new chapters are very vocal. People First held a retreat and spent a lot of time discussing and developing its message. Their goal was to have a unified message that all members would be able to easily explain. A brochure and other information were printed with this message. People

First will have a big display at the Disability Summit the week of October 22 and encouraged everyone at the Summit to view the display. Their website, [www.peoplefirstla.org](http://www.peoplefirstla.org) has been launched and a link will be put on the DDC website.

- Partners in Policymaking – Kevin Hill reported to the committee that Partners in Policymaking is getting ready to select participants for the class that starts in January. Lynda Huggins has agreed to stay on as the coordinator of Partners. Forty two applications have been received for the program. Kevin Hill, Ida Miarelet and some graduates will participate on the selection committee to select participants for the upcoming class.
- LaCAN
  - LaCAN reported that there were 105 confirmed candidate visits to date. This is a remarkable effort and everyone is encouraged to continue visiting the candidates.
  - LaCAN leaders and FHF directors will participate in the LaCAN Kickoff on November 6 and 7 in Alexandria. Agenda items for the Kickoff include discussion of the upcoming Legislative session. LaCAN leaders will schedule visits with the new legislators after the election to educate and inform them about disability related issues. At the Kickoff LaCAN leaders will refine their message for the upcoming legislative session including the LaCAN legislative agenda. LaCAN will also make plans for the regional round tables. These round tables will be very critical due to all of the new legislators. These legislators will be invited to the round table for personal interaction with persons with developmental disabilities and to hear their stories. The rally will be held at the State Capitol again this year around March of 2008.

#### D. ACT 378 SUB-COMMITTEE – Jeanne Abadie

##### The Act 378 Sub Committee

- **Louisiana Rehabilitation Services**

Paige Kelly reported that the LRS Supported Living program was going well. The extra \$200,000 allocated by the legislature this year allowed more services being delivered and increasing the number in the program by approximately 18 more people. The additional funds allocated were used to increase the number of people serviced in this program and was not spread around to other centers.

- **Office of Mental Health**

The Office of Mental Health held a workshop to train the people who are in charge of dispersing the Act 378 money. Sandee Winchell and the OCDD staff participated in this workshop due to having more experience on how to get the money spent. The training provided discussion on the principles of Act 378 and how the money can be spent. OMH staff participating in the training expressed surprise at how flexible the requirements are to spend the money and how much it can actually help a lot of people.

The children's issues all seemed fine except no figures were provided for Metropolitan Human Services District. The adult program had the same problem in that region. The region was allocated \$50,000 and has \$48,700 remaining. This causes great concern particularly with the mental health problems in the New Orleans area. There are four people being discharged from hospitals and they will be expected to receive funds from Metropolitan.

Sharon Dufrene indicated that if this trend of not spending funds in such a needed area continues into next quarter she will recommend for the Council to send a letter to the Metropolitan Human Services District Board requesting for them to look into this much more closely and address this issue.

Kay Marcel questioned about the family subsidy money for OMH not being spent down. When investigated, some things were discovered that made it difficult for families to spend the funds such as caps on how much to spend in various categories. Ms. Winchell stated that that was one of the reasons that Robert Levy provided the training and asked Ms. Winchell and Brenda Boyd (from OCDD) to participate. Ms. Winchell and Ms. Boyd conducted the entire morning session of the training for all regional OMH staff who implement the Act 378 program. Ms. Winchell presented the position that there should not be any caps and the program was designed to be flexible in allowing families to serve as the decision makers. This was to get the regional staff to realize that it was not designed to have the professional as the decision maker. It was discovered that a lot of the staff were new and did not know that the money could be spend that way. The staff stated they would go back and be more flexible and will allow families to spend the funds. She was encouraged by this and feels they will see better results in the future.

- **Office for Citizens with Developmental Disabilities**

OCDD reported that things are moving in a number of areas as indicated in their report to the Council. One issue noted was that there is still not a Memorandum of Understanding between DHH and the Districts and Authorities so the Districts and Authorities have no obligation to report what they do with their funds. However, many of the districts continue to provide this information. At this time they are trying to work out a Memorandum of Understanding.

- **Developmental Disabilities Council**

The two contracts that the DD Council has have no major issues.

The Federation of Families for Children's Mental Health was requested last meeting to show the outcomes for the people they serve. The Federation of Families provided a lot more information in their report and it is a lot more than the committee had time to discuss. It appears that things are going fine with no issues to report.

Northwest INCS reported that they are having issues trying to make sure that the funding they currently have is adequate to cover pay increases for their direct care staff. Northwest INCS requested additional funding to support the increase in DSP wages. There will be a recommendation from the Executive Committee to address this.

7. UNFINISHED BUSINESS – Sandee Winchell  
None to discuss.

8. NEW BUSINESS – Sam Beech

Ms. Beech indicated that the recommendation for the Council’s Legislative Agenda, as discussed in the Executive Committee, was for funding to support 3,000 waiver slots, alignment of resources with demand, housing legislation, transportation legislation, and to create a youth transition core team.

Lois Simpson questioned the transportation initiative. Kay Marcel stated the committee did not develop the details of these initiatives; these are just the areas where they felt there was a need and had been brought up by council members at previous meetings. These will need to be worked on and developed into specific strategies. Ms. Simpson stated that the Advocacy Center has identified transportation as a need for people in rural areas and they would like to join forces on this agenda item in particular. The Advocacy Center is looking into what other states have done in terms of some kind of voucher system for transportation. Jeanne Abadie said that there is a possibility that some amendments will be proposed for allowing DSPs to perform nursing tasks and asked that it be added to the legislative agenda.

Motion Passed Moved to accept the recommendations of the Executive Committee with the addition of the DSP nursing issue for the Council’s Legislative Agenda by Lois Simpson. Seconded by Trudye Jones. Motion passed.

FHF Executive Director’s Qualifications – The Executive Committee met and discussed the issue extensively. The Executive Committee submitted recommendations to the Council for consideration. The recommendations are that the FHF Director must be the parent, family member, or direct care giver of an individual with a developmental disability or a person with a developmental disability and someone who has extensive personal knowledge and experience in disability issues. The Executive Committee had determined that it may be difficult for some FHF Centers to find an Executive Director with the aforementioned qualifications. It is therefore also recommended that the Council develop a formal mechanism whereby the FHF centers may seek a waiver from the council to allow an applicant who is qualified and experienced in the area of disabilities issues, advocacy for individuals with disabilities and/or non-profit management. The applicant may not meet the developmental disability requirements above, but must be a parent, family member, or direct care giver of an individual with a disability or a be a person with a disability. The Committee recommends that the current FHF directors be grandfathered in and

exempted from the previous recommended requirements. A verification form will be signed by the Executive Director and board president.

The Council discussed this issue at length and representatives from Families Helping Families were allowed to address the Council. Some of the comments made by Council members are below:

- It was questioned whether the guidelines defining persons with developmental disabilities be Federal or State. It is the Federal guidelines.
  - Concerns were for children with severe persistent chronic mental illness would not be included under the definition of DD. It was confirmed that it will be included in the definition of DD.
- Another member stated concerns and does not think the council should tell the independent FHF centers who they could hire. This member is uncomfortable giving any mandates as to controlling who the FHF Board could and could not choose as their Executive Director.
  - It was discussed that it was hoped that several applicants would meet the criteria, but in the event the best candidate does not meet this criteria the Board could apply for a waiver.
  - Another Council member stated that DDC started FHF and directed them on their path. One council member expressed the need for the Council to let go and allow FHF to make their own decisions instead of the Council continuing to try to run FHF.
  - Other positions were that as long as the Council is responsible for the funds going into the centers it has to be concerned with and responsible for the outcomes.
  - A suggestion was to have a standard that the Center makes a concerted effort to hire someone per recommendation. It was noted that saying that the Executive Director is a family member of a person with a disability necessarily shows that you are family directed.
  - Another perspective was that the Executive Director needs to have the skills to run the organization.
  - Another concern is that FHF has taken on such a new scope in the last few years that it should have a mandate that the Executive Director have real life experience with families. A fear of having FHF lose the focus of why they were created was expressed.
  - It was questioned as to what gives the DD Council the legal authority to mandate anything. FHF has a standard of operations that they have already accepted.
    - This was responded to that DDC has conditions within their contract and the Council can vote to amend the contract with each FHF.
  - It was stated that you can have a great belief in an organization, but it is different when you actually live and have the experience of what we are asking for.
  - Another fear was this requirement will have FHF strictly focused on developmental disabilities. FHF should encompass all with a disability.

- It was noted that the Executive Director position is the one position that helps to sustain FHF and their standard of organization. FHF should be led by a person with a developmental disability or a family member, parent or care giver.
- Recommended that rather than changing a contract, as a council, come up with a resolution that it is the council's wish that in order for these entities to fulfill the original intent of their goals that it would be best done through administration of those organizations by a person with a developmental disability or family member of such without trying to mandate something through a contract.
  - Comments were made that because the Council is accountable to the legislature regarding the funding of these programs, the Council has more at stake than just making a recommendation and this just strengthens the standards that are already there.
  - FHF representatives stated that they make every effort they can to have the person that is serving those contracts be a person who has life experience with developmental disabilities but not all contracts that support FHF require that the Executive Director be a family member of someone with a certain type of disability.

Discussion ended. Motion to call the question and end discussion moved by Kay Marcel. Seconded by Jared Armstrong. For – 6. Opposed – 4. Motion Passed – Moved to accept Executive Committee's recommendations by Sharon Dufrene. Seconded by Johnnie Morris. For – 8. Opposed – 7 Abstention by Willie Martin.

Committee Recommendations – Committee of the Whole met yesterday to review proposals for monies available for contracts that have not been obligated. The Planning Ad Hoc Committee suggested funding the La Youth Leadership Forum, Partners Reunion, Innovations in Education Child Care Training and stipends for three FHF.

Motion Passed. Motion to accept recommendations by Willie Martin. Seconded by Ida Mialaret For – 14. Against – 0.

Recommendation to increase funding to Northwest INCS to allow a pay increase for DSP with \$6,011 available to pass on to this organization. Original contract was \$105,000. This is a state funded contract with Act 378 funds and these additional state funds will be added to the contract. These funds were given to the Council by DOA. Six persons are served under this contract.

Motion passed. Motion to accept recommendation by Kay Marcel. Seconded by Johnnie Morris. For – 15. Against – 0.

## 9. COUNCIL MEMBER REPORTS

### A. HUMAN DEVELOPMENTAL CENTER- Phil Wilson

Dr. Wilson submitted a written report at the meeting. He apologized for the report not making it to the Council before the mail out. It will be emailed to Shawn Fleming for distribution to Council Members.

Dr. Wilson reported on the following:

- In late July the LSU Human Development Center hosted a four day institute on Autism Spectrum Disorder. This is the first time this activity was done. It was funded by the Louisiana Department Of Education. Ninety people attended with a waiting list of 30 people. HDC is in the process of planning and will advertise another Autism conference very soon. It is being scheduled for November.
- The agenda for a two day conference hosted by HDC in New Orleans on April 28th and 29<sup>th</sup>, 2008 is being planned. Several nationally and internationally known presenters will be key note speakers. This conference will cost around \$80,000.
- HDC is participating in the Power of Three Conference in Alexandria. They will have over a dozen poster presentations and three platform speakers. HDC is funding the key note speaker and a couple of other speakers at the conference.
- The HDC receives their funding in a five year cycle. They expect their RFP to come out for the next five year cycle on or around October 24<sup>th</sup>. They are reforming their constituent advisory council and are in the process of soliciting input from constituents for their five year plan.
- Dr. Wilson stated that Tuesday afternoon he received a call from the chair of Association of University Centers on Developmental Disabilities (AUCD) saying that the National Institute of Health had provided some funding for Autism Spectrum Disorders. This is to bring together state teams to a conference to hear what each state is doing in the area of Autism and Autism Spectrum Disorder. This will take place around late February or early March. It will probably be hosted in New Mexico. As a member of Region 6, HDC has been invited to send a team. HDC will be charged with organizing for the State of Louisiana. It is anticipated that as a result of these meetings, the teams will go back to their states and develop some action plans and mini-grants could be implemented. HDC will be looking for input from the Council and persons they represent who are actively involved in the area of Autism.



## B. ADVOCACY CENTER – Lois Simpson

Lois Simpson reported on the following:

The Advocacy Center's priorities for the coming year do not change much from year to year.

- The first priority is physical and program access. The Advocacy Center is committed to making the physical environment and their programs accessible to people with disabilities, focusing on programs with the local, state and federal governments regarding physical accommodations in restaurants, health clubs, movies or any place open to the public.
- The second priority is having services and supports integrated into the community to the maximum extent possible. One focus area in this priority is with Mental Health services for children. This is specific due to the lawsuit filed for all children eligible for those services. Part of that larger lawsuit was talking about services for children with mental health needs which are still not available to every child in need. The next issue is monitoring and having some impact on the implementation of the Money Follows the Person grant. The area of mental health rehab services suffered with Hurricanes Katrina and Rita and a goal of the Advocacy Center is to ensure that these services are actually meeting the needs of people they are targeted to meet.
- The third area of focus is in housing. Housing is such an important issue for people for a number of factors. Post Katrina, the Advocacy Center lost a lot of housing staff, particularly in the gulf area. The cost of housing has increased so much that it makes affordable housing very difficult for people with disabilities. There are still discriminatory practices of people in the area of housing. One activity in this focus area involves monitoring and impacting legislation.
- The Advocacy Center's main focus on special education is in regard to the illegal letter of denial of an initial evaluation request. Great strides have been made since the class action lawsuit, but has slowed tremendously due to people not getting evaluated for special education services in a timely manner. Failure to provide education services in the least restrictive environment and illegal denial of school services are also areas that are also addressed.
- Another area of focus is on public benefits, focusing on Medicaid and Medicare and access to medical services.
- People should be protected from abuse and neglect without use of restraints and seclusions. They should receive quality support services, rights of protection and power to make choices. One of the DDC's goals is to get people out of institutions, but not involuntarily discharges. Nursing homes have a bad record of discharging people who cost too much or who are a "problem" in a behavioral area. The Advocacy Center handles allegations of abuse and neglect for persons in institutions. The Advocacy Center visits these institutions on a regular basis and responds to the issues brought to them by people in those facilities. The Advocacy Center is also conducting an investigation of child residential care facilities and anticipates producing a report on those facilities within this fiscal year.

- Another focus is on employment with concentrations on discrimination of employment and rehab services, information and technical services on work incentives.
- The right to self-determination area is focused on rights regarding decision making and self-determination and on legal status issues. There are numerous people in our state who have been interdicted without any notice being given to the individual.
- The Advocacy Center will be operating a toll free hotline on election day and run –off voting providing voting assistance to those in need. The hotline number is 1-800-960-0075.
- The Advocacy Center did file a lawsuit against the Baton Rouge transit system about three weeks ago. The center has been in negotiations with CATS for years. Ms. Simpson will be reporting on that as new information becomes available.

Ms. Fontenot expressed appreciation for Jared Armstrong and Johnnie Morris who are rotating off of the Council and presented them with certificates. She also acknowledged that James Wallace received his certificate on Wednesday evening.

### C. LEGISLATIVE CANDIDATE REPORTS – Council Members

Sharon Dufrene made several visits to candidates in her area. A couple of candidates never returned her calls. Pat Culbertson's wife did a one day internship at the DDC under Ann Farber and Ms. Dufrene spoke with her and she is very supportive. Ms. Dufrene has an appointment with Senator Bill Cassidy who was very instrumental in trying to push through mental health parity. Mr. Reynolds is a candidate with a son with Autism and an ex-wife who is a lobbyist for Autism Speaks and founder of Unlocking Autism. He stated he is on board and to let him know what the Council needs. Franklin Foil also has a son with Autism and stated he is interested in helping with anything for the Council. Another candidate was not familiar with the DD Council so Ms. Dufrene explained to him about Ms. Fontenot and other council members and the purpose and mission of the Council.

Kay Marcel visited with a few candidates in the New Iberia/Jeanerette area. Simone Champagne is the only candidate running for the open seat in District 49 and she is the grandmother of a child with a disability. Four candidates are running for the open seat in District 48. Ms. Marcel met with the top two contenders. Taylor Barras is a president of a local bank. Ms. Marcel complimented him on how accessible the bank is for people with disabilities and he stated that one of his top executives has quadriplegia. Shane Romero is the other top candidate. His father, who held the seat previously, has always been supportive of the Council's issues. All of these candidates have experience with persons with disabilities. LaCAN and FHF leaders also met with several candidates in the area.

Ida Miaralet met with Bill Johnson at the FHF center in Jefferson Parish. She found him interesting and that he had some good things to say about people with disabilities. She sent information through the mail to several other candidates that she did not get the opportunity to meet with in person.

Sam Beech reported that the candidate running for Region 7 Representative is running against an incumbent but is expected to win. Ms. Beech emailed him and found out that he has a grandchild with disability. She emphasized the importance of the survey and getting out and meeting with the candidates.

10. LA. ALTERNATIVE ASSESSMENT (LAA) 1 – REDESIGN – Jeanne Johnson, Louisiana Department of Education (LDOE)

Ms. Johnson presented the Louisiana Alternative Assessment (LAA) 1 redesign. This assessment is designed for children with severe cognitive disabilities. She explained why the assessment is changing and what it will look like. The Federal government requires states to assess all students. Students with the most significant cognitive disabilities may take an alternate assessment. Louisiana designed an assessment specifically for these children and called it Leap Alternative Assessment (LAA). This assessment took two years to develop. The previous assessment was linked to general educational standards but was not aligned to the benchmarks that define the educational standards for each grade level. The original alternate assessment began in 2001 and included three levels of complexity and relied on teacher interpretation to determine the performance level of the student. It was among one of the first alternate assessments in the nation. When teachers were initially approached with the concept, they were not receptive to the idea. This was the first time they were required to do a standardized assessment of the performance of students with significant cognitive disabilities. The No Child Left Behind Act included regulations for every state to develop an assessment program specifying what students needed to know or be able to do by the end of every grade. Alternative assessments were then permitted by the Federal Government to be given and to be scored by Alternative Achievement Standards. The Alternate Achievement Standards had to be linked to what is expected in general education on each grade level or by grade span. Louisiana submitted its alternate assessment for the Federal Government to review and evaluate. It was returned “Approval Pending” indicating that Louisiana did not meet the federal requirements and was in jeopardy of losing IDEA funding. So LDOE developed academic standards that parallel Grade Level Expectations (GLE). The subjects that children with significant cognitive disabilities will be tested on are Language Arts, Math, and Science. Language Arts and Math are going to be assessed for all children that meet criteria in grade spans 3-4, 5-6, 7-8, and 9-10. Science will be assessing grades 4, 8, and 11 only. The assessment will administered in Spring of 2008.

The biggest issue with this test is that it is visual and they know some students have issues with vision that can really affect this assessment. Everything is large print and large pictures and will be administered individually to students. The teacher will read it to the students. A plan is being developed for symbolic gestures for children who communicate this way. There are five informational sessions for the special education directors that will take place at the end of October and the beginning of November. This gives them the opportunity to look it over and see what is going on. The students' scores on this assessment will be included as part of accountability in school performance scores. Instruction will take another jump moving from solely functional to academic. A committee of special educators will come in to see if it meets the academic requirements and see if it is something students can do. Ms. Johnson's email address is [Jeanne.johnson@la.gov](mailto:Jeanne.johnson@la.gov).

This was followed by questions and a discussion.

## 11. STATE AGENCY REPORTS

### A. BUREAU OF HEALTH SERVICES FINANCING – Ruth Kennedy for Jerry Phillips

Ruth Kennedy reported on the following:

- The Family Opportunity Act Medicaid Program was implemented in Louisiana. Louisiana is the very first state to implement this program! This particular Medicaid works with SSI benefits, without the loss of SSI due to income. The DD Council played a major part in getting this program implemented. This program will provide full Medicaid benefits to children who currently reside in households with incomes too high to qualify for Medicaid. This act is for children who are not only uninsured, but underinsured. The premium, which is no more than \$35 per month, is based on the poverty level along with other insurance premium costs. Families will not have to pay the first premium until after the child is enrolled and the child can be eligible for retro-active coverage no earlier than October 1<sup>st</sup> without having to pay back premiums. One important thing about the program that is different from other Medicaid programs is that there is no resource or asset test for this program. It is based on the number of persons in the household and the income. One requirement is that if the parent has insurance available through their employer and the employer pays at least half of the premium, the parent must enroll the child and maintain that insurance on the child. There is no pre-existing loophole with this coverage. Copies of the applications were distributed.

This was followed by a discussion.

B. OFFICE OF MENTAL HEALTH – Robert Levy for William Payne

Robert Levy reported on the following:

- Mr. Levy stated that the report in the packet is self explanatory and encouraged questions from the Council. None were asked.

C. OFFICE FOR CITIZENS WITH DEVELOPMENTAL DISABILITIES – Pete Calamari

Mr. Calamari touched on the following from the report:

- Individual Support Plan (ISP) – it maintains a person’s support needs as the focus; incorporates the Supports Intensity Scale (SIS)/Louisiana Plus in the planning process; utilizes a computerized (electronic) version of the ISP to expedite the approval process and allow for the tracking of outcomes. Phase 1 of the SIS/La Plus training has been completed in the following regions: Region 4, Region 5, and the Capitol Area. The second phase will incorporate things participants learned in the first phase of the project. It is projected that a computerized version of the ISP will be ready for July 1, 2008. By this date training of the support coordinators in every region of the state will be completed.
- Supports Intensity Scale (SIS) and La Plus – Staff completed around 3,000 assessments. Approximately 1,200 are being used in a reallocation model that is being developed. Another 900 will be added to make the statewide sample representative of the population. The database and model are being refined.
- Quality Enhancement Process – This process allows a self evaluation by reviewing data on OCDD’s performance relative to the outcomes they were responsible for meeting. Initiatives are developed that address the issues identified with the data. This is perceived to assist with a request made by the Federal government to review the Children’s Choice Waiver.
- Early Steps – DHH made the decision to transfer Early Steps to OCDD effective July 1<sup>st</sup>, 2007. OCDD hopes to increase the number of children determined eligible and being served. Because of a decrease in the number of children registered for the program there was a decrease in the budget.
- Greater New Orleans Supports and Services Center (GNOSS) (formerly Metropolitan Developmental Center) Update – refer to report
- Transition Project Update – Took a lot of effort, thought and collaboration in the successful transition of around 240 people from the institution (GNOSSC) to other living arrangements of their choice. Around 60% of the population transitioned voluntarily to community-based living options. OCDD detailed a partnership with providers where for two years after the transition, they would work in a defined manner with providers and families to assure the successful transition of people to their living and working areas.
- Residential Options Waiver – refer to report.

#### D. OFFICE OF PUBLIC HEALTH – Betsy Snider for Sue Berry

- Betsy Snider touched on the following from the report:
- There was a training held for OPH staff who are direct service providers for children's healthcare needs. The big focus at this time is care coordination and healthcare
- Transition Clinics will begin in New Orleans with Dr. Maurice Shawls who is the only Pediatric Rehabilitation Physician in the state of Louisiana. The contract is in works
- Medical home activities are Tiger Care at LSU in New Orleans and one in Bogalusa. A third one is beginning in Kenner. This program puts a designated care coordinator in large pediatric practices and the focus is on identifying children with special healthcare needs and making sure they are linked to all of the community programs and organizations, and advocacy groups as well as teaching for the families.
- The Speech and Vision Program is now screening 95% of the newborns in Louisiana. The focus is to get children with hearing loss into rehab for early intervention.

#### 12. ANNOUNCEMENTS

Ms. Fontenot announced the next quarterly Council meeting will be held in Baton Rouge on January 16-17, 2008. Orientation will begin on January 15, 2008.

#### 13. ADJOURNMENT OF BUSINESS MEETING

Motion Passed - Moved to adjourn the meeting. Jared Armstrong. Seconded by Johnnie Morris.

The meeting adjourned at 2:59 p.m.