

**LOUISIANA DEVELOPMENTAL DISABILITIES COUNCIL**  
**January 17, 2008**  
**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 Kay Marcel 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  
Sam Beech  
Susan Berry, OPH  
Lynn Cannon  
Sharon Dufrene  
Melissa Fayard  
Lynette Fontenot  
Rocky Fusilier  
Laura Head  
Simone Honore-Chretien  
Kathy Kliebert, OCDD  
Billie Ruth Kvaternik  
Shelia Madison  
Kay Marcel  
Willie Martin  
Ida Mialaret  
Heather Mobley  
Nanette Olivier, DOE  
Jerry Phillips, BHSF  
Matt Rovira, GODA  
Debbie Schilling  
Lois Simpson  
Phil Wilson, HDC

C. MEMBERS ABSENT

Donna Breaux  
Trudye Jones  
William Payne, OMH  
Roseland Starks, LRS  
Godfrey White, GOEA

## E. GUESTS IN ATTENDANCE

Dora Chandler – Guest of Lynette Fontenot  
 Sheryl Doga – Guest of Lynette Fontenot  
 Frances Hilburn  
 Robert Levy – for William Payne, OMH  
 Martha Whitlock  
 Barbara Fayard – Guest of Melissa Fayard  
 Karen Scallen  
 Paige Kelly  
 Rosemary Morales for Roseland Starks, LRS  
 Shelia Blanche– Guest of Billie Ruth Kvaternik  
 Kay Lewis – Families Helping Families of Greater Baton Rouge  
 Yvonne Bell  
 Susan Benoit

## 2. MINUTES OF APRIL MEETING

Ms. Fontenot entertained a motion to accept the minutes from the October meeting. Ms. Cannon stated that the attendance form showed Kathy Kliebert as present but the minutes listed her as absent. She also stated that neither she nor Al Hitt were listed as present under the guest list. Ms. Winchell stated it would be corrected.

Motion Passed - Moved to accept minutes with corrections.

## 3. CHAIRPERSON'S REPORT – Lynette Fontenot.

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

- **Disability Summit**

On October 24<sup>th</sup> and 25<sup>th</sup>, Ms. Fontenot represented the council at the Disability Summit in Alexandria. She was very impressed by the movie and presentation of Diana and Kathy's story. These ladies are roommates and take care of each other with the help of direct support staff. They had been in an institutional setting for years and now live interdependently and support each other. A silent auction was held that included a framed print of Ms. Fontenot's donated artwork.

- **Inclusive Schools Art Contest**

In an effort to provide more awareness of the Inclusive Arts contest, this year the Council took the contest a step further. On November 3<sup>rd</sup>, the Inclusive Art Contest winners were exhibited at Cortana Mall in Baton Rouge. Ms. Fontenot's artwork was also exhibited along with a video demonstration of her producing a painting. Many individuals stopped by to view the winning entries, Ms. Fontenot's video and artwork. Ms. Fontenot thanked all of the council staff who helped prepare the exhibit. She also thanked Christie Cormier who worked so hard framing all the winning entries and exhibiting the students' artwork.

On December 5<sup>th</sup> Ms. Fontenot had the honor of speaking at the Inclusive Arts Contest awards ceremony at the Claiborne building. In addition to her opening address, she also spoke about inclusion and how inclusion affected her life. Ms. Fontenot has been included by her family and community for her entire life. Inclusion has brought her to where she is today and to the position of chairperson of this council. Craig Blackburn was also invited to speak about his life and accomplishments. Another inclusion success story! It is always a pleasure to hear Mr. Blackburn speak. Sandee Winchell and Patrick Dobard, Special Confidant to Superintendent Pastorek, presented the awards. After the ceremony the winners were recognized at the BESE Board meeting. Ms. Fontenot knows the ceremony left an impression on those attending, because she received feedback from one of the students and her family. She also met the art teacher of one of the participants during the exhibit at the mall. The teacher stated she was very impressed with the entire program and is already planning to have her students submit entries in next year's contest.

Ms. Fontenot thanked Robbie for her hard work.

- **Annual Trip to LSU School of Medicine**

On November 8<sup>th</sup>, Ms. Fontenot made her annual trip to Shreveport to make her presentation to the allied health students at LSU School of Medicine. These are students who will be professionals working with people with disabilities and need to see what inclusion can and does accomplish.

- **Meeting with Representative Champagne**

On November 26<sup>th</sup>, Kay Marcel and Ms. Fontenot met with Simone Champagne, newly elected representative in District 49. Representative Champagne was very personable and was very interested in learning about the Council and its goals. Ms. Marcel and Ms. Fontenot felt very good about their visit and feel sure Representative Champagne will be a representative who will advocate for people with disabilities. Rep. Champagne said that she had a lot to learn but is willing to work with the Council.

Kay will also report on the visit with Representative Champagne under legislative visits.

- **Governor's Awards Ceremony**  
 December 14, Ms. Winchell, Ms. Chandler and Ms. Fontenot attended the Governor's Awards ceremony at the Governors Mansion. The program was very well prepared and Matt Rovira did a great job speaking and presenting the awards. The awards went to very deserving individuals. The Council is so proud of Donna Breaux and her family who received the Family of the Year Award and James Wallace who received the Distinguished Merit Award.
- **Region 4 Legislative Round Table**  
 Ms. Marcel and Ms. Fontenot attended the Region 4 Legislative Round Table held on Thursday, January 10th in Lafayette. Linda with LaCAN and Yvonne with Families Helping Families were well prepared and the discussion was very informative.
- **DD Network Meeting**  
 Ms. Fontenot reported that there was not a DD Network meeting due to the change in administration. We will schedule the meeting with Alan Levine, the new Secretary of DHH, in the near future.
- **Executive Committee Meeting**  
 The Executive Committee met on Tuesday, January 15th. The Committee discussed the Judge Rottenberg Center, a private institution in Massachusetts, where children with Autism and behavioral challenges are given electric shocks throughout the day. The committee recommended the Council sign on to a letter that is taking a position against this cruel, inhumane and degrading treatment. This will be voted on during new business.

The Committee next discussed adding a \$3 wage increase for Direct Support Professionals to the Council's legislative agenda. This increase is necessary in order to address the severe shortage of DSPs in the community and ensure a high quality of services for people currently receiving waiver services and those the Committee is hoping will get a waiver slot as a result of the 2008 legislative session. The Committee approved this recommendation for the full Council which will be voted on during new business.

The Committee also recommends that the staff develop positions on legislation that is initially introduced during the session and send these positions to the Executive Committee for approval since the session begins before the April council meeting.

Ms. Winchell informed the Committee that she prepared the materials for Council members to begin making legislative visits and she will distribute these during her Executive Director's report rather than send them through the mail as we have done in the past. This will allow Council members to ask questions and let Council members in each region get together during break to make plans for their legislative visits. As emphasized at orientation, legislative advocacy is one of the most important Council member responsibilities, so Ms. Fontenot encouraged every Council member to take this responsibility seriously and make these visits. The staff will provide whatever support Council members need to assist with the visits.

The committee next discussed the Council's participation in the next Louisiana Disability Summit. Ms. Winchell provided information on the 2007 summit held in Alexandria in October. Over 400 people attended, many of them providers, but also a good number of self advocates. Not many family members attended. The planning committee for the next summit wants a large time commitment from the sponsoring organizations. The Executive Committee recommended that the Council not participate as a sponsor of the next summit. This will be voted on during new business.

The balance of the Council travel stipend fund remains as \$1963.

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

Ms. Winchell discussed the following:

- **The Disability Summit**

In response to a question, Sandee Winchell stated that her personal opinion was that the attendance at the Disability Summit was largely providers, but there were a good number of self advocates there. There were not many family members represented. The conference itself made a substantial amount of money, around \$75,000 in profit. It was Ms. Winchell's understanding that if the Council wishes to participate in the next Summit in 2009, it would not be necessary to put up any money. However, the Summit Committee is asking for a strong time commitment - around one meeting per month and Ms. Winchell stated that we do not have enough staff available to commit to that kind of planning. Ms. Dufrene inquired as to whether the Council can participate on a different level. Ms. Winchell indicated that the Council will absolutely have a display board and can participate in other ways.

Lynn Cannon inquired about who holds the funds from the profit of the Summit. Ms. Winchell indicated that a non-profit organization is being formed to hold and distribute the funds. Karen Scallan stated a specific account was set up for the Summit and the American Association on Intellectual and Developmental Disabilities (AAIDD) has information on who has authority for the account. Ms. Winchell stated this issue will be further discussed and voted on under New Business.

- **Donna Breaux**

Ms. Winchell stated that Donna Breaxu apologized for not being in attendance at the meeting. Ms. Breaux asked Ms. Winchell to convey her thanks for the cards and support from the Council from her and her family. And Ms. Breaux expressed her thanks to the Council for their donation to the Kayla Breaux fund.

- **Advocacy Activities**

Ms. Winchell stated that the Council wrote a letter to the governor expressing support for Kathy Kliebert to remain as the Assistant Secretary of Office for Citizens with Developmental Disabilities (OCDD). The Council also wrote a letter to the new DHH Secretary, Alan Levine, welcoming him to his new position and expressing support for Ms. Kliebert in her position at OCDD.

The Council also wrote a letter of support for the Human Development Center to accompany their five year application to the Administration on Developmental Disabilities.

- **Executive Summary/Program Performance Report**

The Council submitted its annual Program Performance Report (PPR) to the Administration on Developmental Disabilities on time. Ms. Winchell recognized Kandi Smith's work on this report. Ms. Winchell noted that in the packet received before the Council Meeting is an Executive Summary of the PPR which shows what has been accomplished over the past year at the Council. The summary will be sent to Louisiana's Congressional delegation, State Legislatures, State Agencies, Families Helping Families and others with an interest in the Council. It will be posted on the Council's website.

- **Community and Residential Services Association (CARSA)**

Ms. Winchell had a meeting with CARSA representative per their request. CARSA originally requested to Kay Marcel and Ms. Marcel requested that Ms. Winchell meet with them instead. Ms. Marcel was a member of the Medical Advisory Council of the Governor's Office and submitted recommendations for the advisory council report. A CARSA representative stated that Ms. Marcel's recommendations were inline with a lot of CARSA's concerns and issues. There was agreement on the DSP wage increase. Another area of agreement was the ultimate goal of cutting down on paperwork and spending more time and resources directly with serving people. CARSA supports an additional 3,000 waiver slots. They are interested in working together with the Council. Debbie Schilling requested that Ms. Winchell pass on information received from CARSA.

- **National Association of Councils on Developmental Disabilities (NACDD)**

During the NACDD Conference Ms. Winchell discovered that California has an entitlement program for community services with over 300,000 people with developmental disabilities 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.

- **Permanent Supportive Housing Units**

Matt Rovira asked how the additional 3,000 housing slots are managed. Kathy Kliebert stated it is in collaboration between the Department of Social Services and Department of Health and Hospitals to work with lead agencies for distribution to be sure the slots are provided to persons with disabilities.

- **Legislative Visits**

Ms. Winchell referred to handouts provided during the meeting and indicated that they were distributed at the meeting rather than the mail due to the attachments specific to each Council Member. The Council's five year plan has a strategy that Council members make Legislative visits in teams according to region. The goal is for Council members in each region to get together in teams and visit the members of the Appropriations Committee, the Senate Finance Committee, the House Health and Welfare Committee, and the Senate Health and Welfare Committee. Each team should inform the legislator about the DD Council and its mission and goals. The teams also discuss the Council's legislative agenda for that particular year. If team members have difficulty coordinating schedules, members should go alone or with whomever else is available. Ms. Winchell stated the Committee assignments have not yet been made, but when they are, members will receive an email with the names of legislators filled in under the corresponding committees. She also explained the specific information that should be left with the legislators.

Ms. Marcel stated that on the handout "12,635 and growing..." that under the second bullet under Number 1 needs to be changed to "more acceptable pace" instead of "reasonable pace" due to "reasonable" being a legal term and court decisions in other states regarding waiting lists either are or are not moving at a reasonable pace. Lois Simpson suggested using "steady" instead of "acceptable" due to the qualitative meaning suggesting we are accepting the wait. It was agreed by the Council to use "steady pace". Ms. Winchell asked that each person remove this paper from their packet and a new one would be e-mailed or mailed to them for distribution to the Legislators.

Ms. Winchell encouraged everyone to contact and get help from the LaCAN leader in their region to accompany them on the visits, especially if council members do not have another member to accompany them. Ms. Fontenot also stated that she will accompany anyone if they ask her to assist. Ms. Dufrene suggested for each team to get a "report card" or indication of their legislator's voting records and/or support before the visit. Ms. Marcel stated that anecdotally we know the Legislators who have done things but supported Ms. Dufrene's suggestion. Ms. Winchell stated the only vote on a developmental disabilities bill is Senate Bill 98 from last year. The staff can provide the votes on that bill and can disseminate the votes on a few other key bills. Ms. Simpson referred to a biography in Legislative books to assist our information on where the Legislators have volunteered.

Ms. Abadie asked how many slots OCDD had requested. Ms. Kliebert stated that the OCDD requested 1,000 waiver slots through the Division of Administration and they are down to 700. Mr. Phillips stated his office requested a parallel number of waiver slots.

Ms. Winchell stated she will e-mail the letter to be left with the Legislators because it has information in red that needs to be filled out to be applicable to the Legislator and the Council Member.

Facts sheets on the Council and the waivers are also included in each packet. The waiver information will help educate the Legislators. The team leaders were given DD Council folders, letterhead and brochures along with copies of the facts sheets.

Ms. Kliebert stated that due to the DSP wage increase the cap on the Children's Choice waiver is \$17,000, not \$15,000 as indicated in on the fact sheet. Ms. Winchell said a corrected copy would be emailed out.

Ms. Marcel stated that each team member will report on their legislative visits at the next council meeting. Ms. Winchell asked Council members to complete a legislative visit form after each visit and send to the DD Council office.

## 5. BUDGET REPORT – Shawn Fleming

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

Included in the packet handed out this morning is the December budget. The November budget was mailed out. Mr. Fleming indicated that the amount in salaries will have adjustments made to it due to new people being hired. The savings from salaries and related benefits will be placed into contracts. These additional funds in contracts will cover some council funding decisions made at the last meeting. In summary, the contracts budgeted amount will increase and the salaries and benefits budgeted amount will decrease by the next Council meeting.



The budget variance in the second to last column refers to the difference between what was actually expended and the amount expected to have been expended by this time of the year. The variance in the contract budget is due to the fact that some contracts have been slow to get processed and a couple of invoices from contractors have not been submitted.

## 6. COMMITTEE REPORTS

### A. Self Determination/Community Inclusion/Housing - Kay Marcel

Kay Marcel stated the Self Determination Committee met Tuesday afternoon. The meeting began with Ms. Winchell giving updates on LaCAN. Ms. Winchell reported the annual kickoff was held for LaCAN Leaders and Families Helping Families Directors last November in Alexandria. The evaluations indicated that the participants perceived the event was successful and useful. They finalized and voted on the Legislative agenda for LaCAN which includes funding for 3,000 NOW slots. They also included a request for funding for a \$3 wage increase for DSP. The Kickoff also allowed for veteran LaCAN leaders to provide strategies and tips on advocacy efforts and activities.

Ms. Winchell reported that the regional legislative round tables had begun. These are events where Legislators are invited to come to meet on an informal and personal level with families and individuals with disabilities from their region and/or district. The round table event also offers an opportunity for family members and self-advocates to get feedback from Legislators regarding the effectiveness of their presentation.

Ms. Marcel stated plans are underway for the annual Disabilities Rights Rally at the State Capitol. The date has been set for April 23<sup>rd</sup> from 2:00 – 3:30 p.m. She recognized Yvonne Bell with Families Helping Families of Acadiana for chairing the Rally planning committee. The committee is determining how to raise funds from other sources and have other organizations join in sponsoring the Rally. The biggest cost is the transportation for persons from the state to attend.

A recommendation from Council staff was discussed that would base the salary of the regional LaCAN leaders on the average pay scale for comparable employees working for the FHF Center in their region. It was recommended that the maximum wage would be \$13 per hour. This will be voted on under new business.

Becky Zito from People First submitted a report stating that People First has had ten trainings in the last quarter. They have done presentations at other events to gather information on topics that self advocates indicate they want to receive training on. They also participated in the Louisiana Disabilities Summit. People First will be meeting with Lisa Williams of the Advocacy Center to discuss ways they can collaborate and jointly present education training on voting rights. Ms. Zito mentioned the new People First chapter at the LSU-Eunice campus will become active on March 1<sup>st</sup>. She also announced that People First has moved to 606 Colonial Drive in Baton Rouge with the Arc of Louisiana.

The Partners Reunion will be held between July and September 2008. Lynda Huggins, Coordinator for Partners, will pull together some graduates and all DD Council Members who are graduates to help plan the reunion.

It was reported to the Council that Karen Scallan submitted her resignation as Director of Families Helping Families of Louisiana. This may or may not have implications on the remainder of the Council's contract through September 30<sup>th</sup>. The FHF Board will be meeting and the Council is waiting to see what they plan to do between now and September 30<sup>th</sup>.

Other issues discussed were updates Ms. Winchell submitted on Council plan objectives. Ms. Winchell reported on:

Objective #5 addresses educating parents whose children reside in developmental centers on the benefits of transitioning to community based services. Previously the Committee had extended the contract with Evergreen Presbyterian Services to provide these services until March of 2008. They have met the goal of providing information to 25 parents.

Objective #7 involves the reformation of the long term care system to align resources to meet demand through advocacy and education of legislators. Ms. Winchell and her staff have given the Council the information to begin meeting with legislators regarding this initiative.

Objective #10 addresses DSP issues including the wage increase. This is being worked on by the Committee.

The last Objective discussed was #12 that makes Council funds available to OCDD to provide rental subsidies and assist with the transition costs of persons moving out of private institutions and into the community. The Money Follows the Person grant that the State and OCDD received is awaiting approval of the new Residential Options Waiver.

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

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

Ms. Beech welcomed all of the new members who visited during the meeting and stated that all or most will be joining the Health/Education/Employment Committee.

Kandi Smith updated the Committee on the State Plan activities. LaTEACH is represented on the Alternate Diploma Taskforce with the Department of Education. Nanette Olivier informed the committee that the Department of Education had made recommendations for the Alternate Diploma Tracks and it has been deferred once again for discussion at the next BESE meeting. The recommendations are outlined in Ms. Olivier's report to the Council.

The Government Internship has one intern who is in a twelve week work detail with Senator Butch Gautreaux. The Committee was informed that Representative Joe Harrison, who is a new representative, has agreed to hire the next intern sometime in February.

The Jambalaya Project through the Northlake Resource Center has started providing inclusive recreational activities for children ages 6-13 in Ascension Parish. Fall and winter activities have begun and spring activities are being planned.

Project PACT, which provides training of trainers for inclusive practices in daycare centers, will have its first training in Alexandria this month. The training sessions will be held across the state.

Robbie Gray reported on the success of the Council's Inclusive Arts Contest.

Shawn Fleming talked about education monitoring and the determinations being made of Local Education Agencies (LEA) based on their data. The Committee determined it would like someone from the Department of Education to come in and speak on monitoring and other things going on.

## C. ACT 378 SUB-COMMITTEE – Kay Marcel

Kay Marcel discussed the Committee actions:

The Committee received and reviewed the reports submitted by the State Agencies. Ten people are receiving services through the Act 378 Fund and the regional office indicated it anticipates adding additional people within the next few days. They are looking at other alternatives to spending the funds including consideration to providing \$20,000 - \$25,000 to an existing program called Forensic Aftercare. Forensic Aftercare currently serves individuals who are transitioning into the community from the East Louisiana State Hospital.

They understand that these funds are only available through June 2008 and will not be available next fiscal year. It was reported at the last meeting that if the Committee was not satisfied with the report, the Council will send a letter to the Metropolitan Human Services Board to express concerns about the issues of the continuing difficulties of spending money for services that are needed. It was reported in the Times Picayune that the Act 378 funds are not the only money devoted to mental health in New Orleans not being spent. There are also Federal funds available in that region. Lois Simpson and Jeanne Abadie have been interacting with persons on the board who may not be aware of the full implications of what is not happening in that region. Ms. Marcel stated her appreciation for Robert Levy staying on top of the situation and keeping the Council informed. Kathy Kliebert stated that OMH and OCDD have been conducting bi-weekly conference calls with the Executive Director of Metropolitan Human Service District regarding services in that region. She suggested it would help if the Council sent a letter to the board to make them aware of the issues also.

The Committee also received information from Stacy Fusilier from the Region 7 OMH. This information was in response to questions from the last meeting regarding Act 378 funds being spent on the Adult Supported Living Program. Ms. Fusilier stated the services received with these funds are through a contract with Volunteers of America in the Shreveport area for case management for children (Parent Liaison and Parent Advocate). She provided a written and oral report on the services and activities of these programs. The intensity level of support coordination varies depending on the person's needs. This program also provides for an Adult Mobile Crisis screening that can provide evaluation and access to immediate services based on the need. Ms. Fusilier also provided information on a consumer satisfaction survey that was done with the adults receiving services through this fund. The survey revealed that the consumers were aware of the services, were included in planning their goals, a majority indicated the services resulted in an increased awareness of services available to them, all respondents indicated they were making progress, and all respondents agreed that they were satisfied with the support coordination services.

The Committee heard from Louisiana Rehabilitation Services (LRS) about the ongoing supported living program done by Resources for Independent Living in New Orleans. LRS continues to service twenty-two individuals and the committee was very interested in receiving the consumer satisfaction survey. The surveys received indicated that the overall performance of the provider was excellent. The specific issues or concerns will be given by Paige Kelly during the LRS report. It was recommended to LRS by the committee that if they should receive additional funds during the upcoming Legislative session for supported living services that consideration be given to providing those services in regions other than exclusively serving the New Orleans and Baton Rouge regions.

The Office for Citizens with Developmental Disabilities reported to the committee that the maintenance of the cash subsidy list will be changed from

a centralized to regional approach. The Committee requested to be provided with a copy of the manual and for future reports to the sub-committee to include the number of children on the cash subsidy waiting list by region.

The Committee received information on the two projects the DD Council supports. The Supported Living Program in Shreveport is serving six people. It was questioned whether the funding would be available to continue this program with the DSP wage increase. Ms. Marcel reported that additional funds were approved at the last Council meeting to support an increase in the contract to support a DSP wage increase.

The Federation of Families for Children's Mental Health quarterly report is more detailed and reflected a high volume of contacts and support. The report indicated where the people were referred to and the particular need being met. A committee member questioned whether they are serving a cross section of cultures. The concern was whether they are serving Caucasian children and not exclusively serving the African-American population. Ms. Marcel stated the sub-committee requested data regarding ethnicity of population being served.

7. UNFISHED BUSINESS – Kay Marcel

None to discuss.

8. NEW BUSINESS – Kay Marcel

Committee Recommendations:

- LaCAN leaders pay increase with a cap of \$13 per hour. Moved by Willie Martin. Seconded by Bille Ruth Kvaternik. Motion passed.
- Executive Committee report for recommendation for the Council to sign on to the letter against torture, cruel, and inhumane treatment of children and adolescents at the Judge Rotenberg Educational Center in Massachusetts. Moved by Sharon Dufrene. Seconded by Ida Miarale. Motion passed.
- Committee recommendation not to participate as a sponsoring organization in the 2009 Disability Summit. Moved to accept by Sharon Dufrene. Seconded by Willie Martin. No discussion. Motion passed with three Abstentions.
- Committee recommendation to an addition to the Legislative agenda for the Council to add the DSP \$3 wage increase. Motion to accept recommendation by Lynn Cannon. Seconded by Shelia Madison. Motion passed with two Abstentions.
- Ms. Marcel indicated that although we are finalizing our Legislative agenda to go into the legislative session that changes may be necessary due to the legislative process being very fluid. A motion was made to allow staff to modify the Council's legislative agenda when necessary in keeping up with the Council's mission and goal.

Moved by Jeanne Abadie. Seconded by Billie Ruth Kvaternik. Motion passed.

- Ms. Marcel stated there will be a discussion after our “after lunch” speakers regarding the Housing Initiative in Louisiana. We will discuss whether the Council needs to take the lead with housing initiatives or if the council should support activities led by other organizations. Lois Simpson inquired whether transportation was on the agenda. Ms. Winchell stated a copy of the Council’s Legislative agenda was not in the packet, but that transportation as well as housing is on the council’s legislative agenda. However, today’s discussion will focus on housing and include insight provided by the guest speaker on housing. Further direction on transportation issues is needed.

## 9. COUNCIL MEMBER REPORTS

### A. HUMAN DEVELOPMENTAL CENTER- Phil Wilson

Dr. Wilson reported on the following:

- The HDC’s five year proposal to ADD was mailed on January 14, 2008. Dr. Wilson thanked Sandee Winchell and Lois Simpson for providing letters of support for the organization’s proposal. Dr. Wilson stated the main difference between this proposal and previous proposals is the focus on the DD Act required areas for HDC. There are four areas of focus.
  - Interdisciplinary training to build the capacity of people who currently or in the future will provide supports and services to individuals with disabilities and their families.
  - The second area is research. HDC efforts will include Participatory Action Research that provides a new focus in terms of the disability community and the research world. HDC will be asking for individuals with disabilities and their families to participate in the implementation and evaluation of the research. A current project is the Health and Wellness research project. This project is studying the transition into the community to determine whether decline in health is a result of a gap in healthcare providers.
  - The third area of focus is training and technical assistance, model demonstrations and providing direct services. The HDC will continue to do these services.
  - The final area is dissemination. This is an area that HDC needs to address since the buildings in New Orleans were destroyed and the website has not been updated since Katrina. HDC is now focusing on upgrading the website. They are looking for input from the DD Council regarding these issues.
- HDC is having difficulty recruiting more faculty members to New Orleans. Dr. Wilson is optimistic that in the next year or so the corner will be turned on having housing and other amenities available to attract quality candidates.

- HDC has been relatively quiet in the area of Early Childhood. This is due to change in leadership and other faculty leaving as well as building space. HDC is negotiating with UNO to have a role in their campus childcare center. Construction is expected to begin on a new facility.
- Dr. Wilson reminded everyone that HDC is hosting their second institute April 28-29 in New Orleans. This year's theme is Autism Spectrum Disorders Issues and Strategies throughout the lifespan. The cost of registration is high, but HDC will accept any hardships if the Council members are interested in applying.

B. ADVOCACY CENTER – Lois Simpson

Lois Simpson reported on the following:

The written report lists a draft Legislative agenda. Some changes to the legislative agenda have been made as follows:

- The first change is for increased transportation opportunities for persons with disabilities. Transportation has historically been a struggle in Louisiana. The Center does not have enough time before this Legislative session to put together the research to develop a specific request. The center is studying and gathering information about the problems people are reporting with Medicaid transportation services. This agenda item intends to address a broader spectrum of transportation issues based on what other states are doing to provide adequate transportation. Groundwork needs to be laid and funding provided to develop a clear agenda item.
- As indicated in the center's report, the second item was seeking to amend the interdiction statute to allow the interdicted to retain legal counsel to challenge interdiction. Currently the only legal right the interdicted have is to challenge his or her interdiction. However, the interdicted cannot retain legal counsel to represent them. The center is backing off of this issue out of fear that people against persons with disabilities would use this opportunity to make recommendations to make these statutes give persons with disabilities even less rights.
- The center met with Jay Dardenne, Secretary of State, and Mr. Schedler, his Deputy, regarding procedures for voting through absenteeism by mail. Currently, this procedure requires the person prove that he or she has a disability while others without disabilities only have to indicate they will be out of town to vote through absenteeism. Mr. Dardenne admitted that this requirement is to address the tactic used by people wanting to commit election fraud by asking for ballots by mail and removing them from people's mailboxes or coercing the person into asking for the absentee ballot and voting for the person. The fallback position was instead of having to prove one's disability by way of a doctor's note was to prove disability in other ways like, showing you have Social Security Disability, SSI, or any number of other ways. Mr. Dardenne and Mr. Schedler were open to creating a system for a single (once in a lifetime) proof instead of requiring proof of a disability for each election.
- The conversation also included discussion about the requirement for citizens with disabilities to have a doctor's note to receive special

assistance in voting at the polls. Each local voting authority is responsible for accessibility. This requires constant vigilance with addressing this issue since each local polling authority experiences constant changes in administration. The Council could approach legislators regarding accessibility. Approaching the issue from a state level may be more effective than sending letters to each local police jury and municipality without getting any response. Ms. Simpson recommended that everyone continue to provide notice to the Advocacy Center if any polling location does not comply with accessibility laws. There are HAVA funds available for local polling authorities to bring polling sites into compliance. The Advocacy Center will assist with filing formal complaints.

- Anyone who needs assistance voting is not eligible to serve as a poll commissioner. The Center asked the Secretary's office to change this language because even though someone may require assistance to vote, there are positions that people with disabilities could perform at the polls.

Billie Ruth Kvaternik requested Ms. Simpson's group to speak to her group. Ms. Simpson indicated that her office makes presentations and asked Ms. Kvaternik to contact her office to give them details about the request for her group's presentation. The Outreach and Training coordinator is Ms. Stephanie Patrick at (800) 960-7705 x 143. Ms. Simpson provided the direct contact number to avoid going through the Advocacy Center intake system.

#### C. LEGISLATIVE CANDIDATE REPORTS – Council Members

Ms. Marcell and Ms. Fontenot met with one of the new representatives, Simone Champagne. Representative Champagne was very receptive at the meeting. She has been appointed to the Appropriations Committee. She has a grandchild with a rare genetic disorder. She is also very interested in attending Council Meetings. Ms. Marcel and Ms. Fontenot are going to meet with Senator Mike Michot who is now chair of the Senate Finance Committee. They are also going to schedule with more representatives and senators in their region. Ms. Marcel encouraged all council members to visit their legislators.

Ida Miralet 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 a disability. She emphasized the importance of the survey and getting out and meeting with the candidates.

Willie Martin reported on his participation in the Disabilities Summit. His favorite sessions were People First and Families Helping Families. This was the first time Mr. Martin attended and he received a lot of insight and learned a lot that will help him in the future. He arrived on Tuesday and the meeting lasted until Friday evening. He had a wonderful time and thanked the Council for supporting him with this educational opportunity.

Sharon Dufrene expressed how grateful she is to have attended the Louisiana State Autism Conference. It was a very successful conference. The guest speaker at the conference was Temple Grandin – a 60 year old lady with autism who shared her personal experience and research on Autism. What struck Ms. Dufrene the most was when someone asked Ms. Grandin what her most difficult experience was as a person with autism – and she replied “High School.” Ms. Dufrene expressed that one issue that conference topics continue to include is “Autism 101,” when parents today are so knowledgeable that they could present on most of this information. At the Asperger’s Syndrome Conference, a lot of practical strategies were presented by a speech pathologist from out of state. He provided many tools to assist with identification and issues related to the identification of Autism. Ms. Dufrene expressed her appreciation of the help of the Council with allowing her these opportunities.

## 10. HIGHER GROUND DVD AND DISCUSSION

Due to time constraints only brief excerpts were shown of the DVD. Ms. Simpson asked how the video will be used. Ms. Miralet indicated that the excerpts viewed during the Council meeting were not representative of the impact of viewing the entire video. The tapes can be purchased through the Volunteers of America. Dr. Wilson reiterated that it is necessary to watch the entire video. The consensus of council members who had seen the entire movie was that 90% of the video is great, however, there are parts of it that do not represent people with DD well. A request was made to watch the video the Wednesday night of the next Council Meeting. However, the council uses that time to work on the plan so typically there is not time to have a speaker or presentation. Another suggestion was to view it during the Thursday lunch. A shorter version of the movie would need to be used for Legislators. Mr. Rovira asked if it could be targeted specifically for the Legislative Appropriations Committee and the sub-committee on health – but again it would have to be a condensed version. Ms. Marcel asked Ms. Miralet to look into a shorter version of the video. Ms. Fontenot indicated that Representative Champagne would help get it on the Appropriations Committee agenda.

## 11. STATE AGENCY REPORTS

### A. LOUISIANA REHABILITATION SERVICES – Roseland Starks

Rosemary Morales for Roseland Starks offered to field questions since no new information has been added since the report was submitted to the Council. Ms. Dufrene asked Ms. Morales to describe a Randolph Sheppard Station. Ms. Morales indicated that the Randolph-Sheppard Business Enterprise Program provides career opportunities for qualified individuals in the food service field. These are vending stations run by persons who are visually impaired. They are primarily run in Government buildings with a recent first in a private office building. These programs are very profitable and provide a needed service.

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

Robert Levy reported on the following:

- Mr. Levy indicated that the report in the packet is self explanatory and any new questions could be covered by Kathy Kliebert. He asked if there were any questions regarding the written report. None were asked.

### C. GOVERNOR'S OFFICE OF ELDERLY AFFAIRS – Godfrey White

Mr. White was unable to attend the Council Meeting. A written report was submitted to the Council.

## 12. COUNCIL MEMBER PICTURES

LUNCH

13. HOUSING ISSUES – Tammy LeBlanc and Chris Rhorer with the Department of Health and Hospitals reported on the housing initiatives of DHH's Systems Transformation Grant.

## 14. STATE AGENCY REPORTS CONT'D:

### D. OFFICE FOR CITIZENS WITH DEVELOPMENTAL DISABILITIES – Kathy Kliebert

Kathy Kliebert touched on the following from her written report:

- OCDD completed an additional 900 assessments using the Supports Intensity Scale (SIS) La. PLUS and are analyzing the data to use as a part of the resource allocation model being developed. There has been a delay getting the resource allocation stakeholders meeting due to the unexpected death of primary consultant on the project, Gary Smith. OCDD is in the process of finding another set of consultants to facilitate the stakeholders on this initiative. The next stakeholder meeting will be on Tuesday, January 22, 2008 at 1:00 p.m. Ms. Kliebert invited any council member to participate in this important issue for the Council. A report was recently completed and sent out to

the stakeholders. OCDD intends to identify all policy issues through subgroups of the stakeholder committee.

- The National Core Indicators Project involves tracking progress on indicators that have been used by many Developmental Disabilities agencies throughout the nation. It gives OCDD the opportunity to compare itself with other states. The customer surveys are not covering everything OCDD wants covered and they are making adjustments in that area. When OCDD does the first round of looking at these indicators, there will be some face to face interviews and mail out surveys conducted to gain input. It is uncertain whether the size of data collected this year will be adequate to yield statistically significant findings, but it should help for comparison on a national level. Next year's round of data collection will include more face to face interviews and hopefully will incorporate some peer to peer interviews.
- OCDD is in the process of getting the Residential Opportunities Waiver (ROW) approved by CMS. All indications from CMS are positive and OCDD has not had to substantially change the content or the intent of their proposed services. At this point, one of the biggest issues has been professional services that overlap with Medicaid services. CMS has indicated that they are aware that OCDD cannot implement their Money Follows the Person grant without ROW being approved. They are hoping to get approval in the next month or so. The projected date for implementation has been moved back to March 1, 2008. Informational meetings are well attended by providers interested in converting ICFs/DD into community services with a cost neutral switch.
- OCDD and OMH have developed a new program similar to the Neuropsych program at Southeast Louisiana Hospital for adolescents and young adults. OCDD has been requested to have more of these type beds available to prevent long-term institutionalization. The program is projected to last six to eighteen months followed by a return to the community. Twelve beds will be at Central in Pineville. OCDD will be ongoing consultants on the project. Dr. Jay Sevin is working on setting this program up. OCDD is excited about this increased capacity hoping it will prevent long term institutionalizations. This was followed by a discussion.
- Regarding OCDD's expanded budget request, the Division of Administration did not approve any of the initiatives for funding. OCDD is appealing for Early Steps restoration, Autism Services, and Waivers (1,000 initially requested was reduced to 750).
- The hiring freeze has been causing problems particularly since new positions to process waiver slots were just approved through Civil Service. OCDD has submitted a request for an exemption for these positions. It is expected that budget cuts will affect other services.

Council members expressed concern about family members not being paid to care for family members. Ms. Kliebert indicated that Louisiana Waivers are

the most flexible and allow this in some instances. However, there are restrictions on family members who live together.

This was followed by further discussion regarding budget cuts.

#### E. LOUISIANA DEPARTMENT OF EDUCATION – Nanette Olivier

The Autism Task Force met and invited people from other groups to participate. Additional state agency representatives will also be invited. She identified the following three priority areas they will begin to work on:

- Needs assessment
- Marketing: How to get the information out to teachers and school personnel.
- Professional Development

Changes in statewide assessments require students with significant cognitive disabilities to be assessed annually on academic standards. To support this requirement, Louisiana developed the Louisiana Extended Standards and assessments specific to grade levels in the areas of English, Math, Science and Social Studies for children with significant disabilities.

The Alternative Diploma Options Taskforce was established to review and make recommendations for high school exit documents for children with developmental disabilities. The taskforce consists of a mixture of professionals, family members, and agency personnel. Due to concerns about potential recommendations to BESE, the original recommendations were pulled and not submitted at the January BESE meeting. One concern about the recommendations is the drop out rate in Special Education. Children who remain in school don't receive an exit document. Instead they receive a Certificate of Achievement which does not carry any weight. It is not possible to get into college or the armed services with a Certificate of Achievement. The Taskforce recommended offering high school diplomas to children who take all of the required high school courses and take the LEAP Alternate Assessment II. This test is very stringent. The other recommendation was to grant a GED for children who pass the Carnegie units and who pass the Graduate Equivalency Diploma test. It was also recommended that the Certificate of Achievement be kept for those participating in the Alternate Assessment Level I.

Some staff changes at the DOE have taken place. Susan Batson is now the Acting Director of the Division of Educational Improvement and Assistance (DEIA). DEIA is the division that houses Special Education. Dr. Scott Norton is the Assistant Superintendent of the Office of Student and School Performance that houses DEIA. Jena Reedy, the parent liaison, has left the Department.

The question was asked why students need an IQ test to take Alternate Assessment I. Ms. Olivier indicated that while Federal law does not require the use of IQ testing, the Louisiana Department of Education will use IQ and/or adaptive behavior test results to identify the 1% of students who can be considered proficient in the area of alternate assessment.

Ms. Madison asked if it was too late to join the State Autism team. Ms. Olivier stated she will find out and let her know.

Sharon Dufrene stated that a large group of parents of children with Autism would like to see the State team possibly require educators to have a certification to teach children with autism, especially those that are non-verbal. She feels there is no mandate for teachers who teach these children. Ms. Olivier indicated that DOE has funded a project to offer teacher certification and preparation in the area of blind/visually impaired, deaf/hard of hearing, and significant disabilities. Through this project, they are requiring that the group develop Autism courses and to work with the DOE in figuring out feasibility and to set up an endorsement.

#### F. OFFICE OF PUBLIC HEALTH - Betsy Snider for Sue Berry

Ms. Snider reported that the office received some data from the Maternal Child Health Bureau and CDC regarding a survey for children with special healthcare needs. This was first done in 2001 to determine the prevalence of children with special healthcare needs. CSHS just completed a federal block grant that required them to meet national and federal objectives. In 2001, Louisiana was below the national average in all five indicators used for the programs. Current data reveals Louisiana is now above average in all five indicators. The indicators are:

- Families will partner in decision making at all levels of care and are satisfied with the care they receive.
- CSHS will have coordinated, comprehensive and continuous care in a medical home.
- Families have adequate healthcare insurance.
- Services are organized in ways that are easy to use them.
- Children will make appropriate transitions to adult services.

After Katrina, OPH was at 50% staff in New Orleans. Now all but one of these positions has been filled.

The Care Coordination program will be piloted in March. This program will be web-based to enable accessibility throughout the state.

A new brochure has been developed for physicians with information on sub-specialty clinics and where to go for medical and financial eligibility. This is to address the problem of physicians moving in and out of the state. Another brochure will be developed designed to be accessible to everyone.

The birth defect monitoring system covers 50% of the state. There is an unfunded Legislative mandate for the system to cover 100% of the state. To have 100% coverage more staff are needed.

#### G. GOVERNOR'S OFFICE OF DISABILITY AFFAIRS – Matt Rovira

Mr. Rovira had to leave, but left his report to be handed out to the Council.

#### H. BUREAU OF HEALTH SERVICES FINANCING – Ray Dawson

Ray Dawson reported for Jerry Phillips. Waiver opportunities were funded for this fiscal year and are in the process of being filled. The 1,500 NOW slots for this year are expected to be filled by June 30, 2008.

The current status of the Family Opportunity Act is that it was submitted to CMS on November 13, 2007. Medicaid has had two conference calls with CMS to discuss changes that CMS requested. These final changes were submitted on January 16, 2008. CMS has until February 11, 2008 to issue their decision. Currently 55 individuals are certified to receive services when and if CMS approves it. Ms. Marcel asked how many applications have been received. Mr. Dawson indicated that he will let Ms. Winchell know when he finds out that number.

At the current time, Louisiana is waiting on an answer from CMS in regards to their request to cover children through LaCHIP up to 250% of the poverty level. Secretary Cerise received a letter on January 14, 2008 in regards to LaCHIP from several U.S. senators. The letter specifically mentions Louisiana and expresses concerns about CMS imposing limitations on funding and denying states' request to expand their coverage. The senators believe CMS is not in compliance with Federal Statutes. The senators are requesting that CMS reverse their current position and allow the states to use the waiver for these children's health care.

The current Medicaid budget was submitted and is under review by the current Division of Administration.

#### 15. ANNOUNCEMENTS

Ms. Fontenot announced the next quarterly meeting will be held in Baton Rouge on April 16-17, 2008. This will be the planning meeting and will begin at 10:00 a.m. on April 16<sup>th</sup>.

#### 16. ADJOURNMENT OF BUSINESS MEETING

Moved to adjourn the meeting by Debbie Schilling. Seconded by Willie Martin.  
Motion Passed

The meeting adjourned at 3:10 p.m.