

**LOUISIANA DEVELOPMENTAL DISABILITIES COUNCIL
JANUARY 20, 2011
MEETING**

Holiday Inn South

8:30 A.M.

Baton Rouge, Louisiana

1. GREETINGS AND INTRODUCTIONS

- A. Sam Beech, Chair of the Council, welcomed everyone to the meeting. She 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. Beech 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

Sam Beech
Sue Berry, OPH/CSHS
Donna Breaux
Brandon Burriss, GODA
Pranab Choudhury
Mary Elizabeth Christian
Hugh Eley, OAAS
Rocky Fuselier
Don Gregory, BHSF
Laura Head
Valerie Hiser
Julia Kenny, OCDD
Kay Marcel
Andrew Merlin
Heather Mobley
Chasedee Noto
Nanette Olivier, DOE
Bambi Polotzola
Olantha Scott
Lois Simpson, AC
Phil Wilson, HDC

C. MEMBERS ABSENT

Lynn Cannon
Reginald Garey
Michelle Octave, GOEA
Roseland Starks
Nicole Soileau

D. STAFF PRESENT

Shawn Fleming
Paige Freeman
Robbie Gray
Kevin Hill
Derek White
Sandee Winchell

E. GUESTS IN ATTENDANCE

Teresa Milner, LRS
Martha Whitlock
Kelly Serrett, Arc of LA
James Sprinkle, FHF at the Crossroads
Patrice Thomas, Legislative Fiscal Office
Stephanie Mire, Transcriptionist
Rebecca Ellis, LaCAN/LaTEACH, Region 9
Kathy Kliebert, DHH Deputy Undersecretary

2. SUMMARY OF OCTOBER MEETING

Ms. Beech requested a motion to accept the summary from the October meeting.

Phil Wilson stated that on page 6, second paragraph it should read "...inter-disciplinary training for all professionals."

Motion passed. Motion to accept summary with correction made by Mary Elizabeth Christian. Second by Val Hiser. Passed without objection.

3. CHAIRPERSON'S REPORT –Sam Beech

Ms. Beech reported on her activities of the past quarter as follows:

Ms. Beech went on legislative visits in Region 7 with LaCAN leader Duane Ebarb, Families Helping Families Director Chanel Jackson, Council member Laura Head and other constituents.

Ms. Beech participated in a conference call about the regional rallies that are going to replace the state rally held at the Capitol in previous years.

On October 28th, Region 7 hosted the LaCAN Roundtable. Five representatives, two legislative assistants, and about 35 people attended. One mother of a son with autism shared how long they have been on the waiting list. Now they are looking forward to finally getting services. It made a big impact on the legislators in terms of what it would mean to the mother if her son could not receive the waiver.

On November 15th Ms. Beech attended the Administration on Developmental Disabilities (ADD) listening session in Dallas. These listening sessions are being held across the nation to hear experts, family members, self advocates, and providers share their ideas about all facets of life of a person with disabilities and develop a vision for the future. All the information gathered from around the country will be on the ADD website in March for public comment. The Council staff will send an email to Council members when this is available.

A discussion followed.

Executive Committee Meeting on January 19th

Ms. Beech shared a revised evaluation form for Council meetings. The committee hopes that this new format will encourage everyone to offer suggestions to improve the meeting. The format of the meetings was changed a year ago to be more proactive, meaningful and to encourage more discussion.

An ad hoc committee will be formed to revamp orientation. Olantha Scott, Val Hiser, Donna Breaux and Ms. Beech volunteered to serve on the ad hoc committee. The National Association of Councils on Developmental Disabilities (NACDD) contacted

Sandee Winchell and asked for information on the Council that they could share with Louisiana congressional members. Federal funding for the Council is in jeopardy of being cut by 5 percent or more. Council members were encouraged to visit their Congressmen and Senators in their district offices. Ms. Winchell will contact Council members that are going to be asked to be a lead person for each of these visits. The committee also discussed possible reasons why some members are not making legislative visits and what assistance or support could be provided to help facilitate these visits. The staff will insure that the LaCAN leader or the LaTEACH coordinator in each region is contacting the Council members and inviting them on legislative visits. Next year the staff will print each legislator's letter and stuff the Council folders with the fact sheets prior to mailing them to the Council members. In addition to these suggestions Ms. Beech asked for comments or ideas on how to make the visits easier.

A discussion followed.

In April, the Council will develop a brand new Five Year Plan. The Executive Committee thought it would be good to review the Mission Statement at this time. The Executive Committee recommended for it to take members' suggestions and draft a new mission statement for approval at the April meeting.

A discussion followed.

Motion withdrawn. Motion to accept the process recommended by the Executive Committee to revise the mission statement made by Val Hiser. Second by Pranab Choudhury.

Motion passed. Motion to discuss the mission statement at the beginning of the April planning meeting and shorten the Council business meeting made by Kay Marcel. Second by Nanette Olivier. Passed without objection.

The Executive Committee recommended the staff develop a draft agenda for the planning meeting and send it to Council members for input. The Executive Committee will meet to discuss the feedback and finalize the agenda for the planning meeting.

Motion passed. Motion to accept the proposed planning process of staff developing a draft agenda, sending to members for input and finalized by the Executive Committee made by Nanette Olivier. Second by Val Hiser. Passed without objection.

Ms. Beech informed the Council that the new plan will not include pre-written goals by ADD as it has in the past. The staff will draft some goals in the new format using our current initiatives as a guide so the Council doesn't go into the April meeting with a completely blank slate. The Council can then delete, revise or add to them.

Ms. Beech referred Council members to the revised list of proposed position papers included in the members' packets. One general paper would state the Council's values and position on inclusion in all facets of society and that people should not be segregated in any way. There will be separate papers on specific topics which would be Community Living, which would address the closure of developmental centers;

Inclusive Education, would include access to meaningful exit options and early intervention services; Workforce Development; Direct Support Professionals; Employment; Transportation; Child Care; Housing; and Health included in the members' packet.

Motion Passed. Motion to accept the plan to develop new position papers made by Val Hiser. Second by Chasedee Noto. Passed without objection.

4. EXECUTIVE DIRECTOR'S REPORT – Sandee Winchell

Ms. Winchell stated the staff moved into the new office and encouraged everyone to come by to see it. The new office address is 626 Main Street, Suite A.

Staff have been very busy assisting with getting information out on the changes in resource allocation. Numerous phone calls and emails have been received from individuals and their families who are dealing with these changes and getting a lot of misinformation from their support coordinators and some providers as well as other people. Staff are assisting OCDD by helping develop questions and answers and getting information out through the Council Facebook page, the website and the LaCAN list serve.

A discussion followed.

During visits to legislators, an issue came up when some legislators wanted to compare costs between waiver services and nursing homes since they considered placing people with developmental disabilities in nursing homes as an option. The staff developed a new fact sheet, "A home of their own, not nursing homes for people with developmental disabilities." One legislator quoted a cost for nursing homes at about \$30,000. However, that is not really a comparable cost to waiver services because anyone with a developmental disability placed in a nursing facility must be provided specialized services and what is called "active treatment". The cost of those services would be over and above the cost of the nursing home. In addition, the Medicaid Act requires that prior to going into a nursing home someone with a developmental disability must be screened to determine whether their needs could be met in the community.

Ms. Winchell spoke on the meeting format mentioned by Ms. Beech and asked if staff can help facilitate Council member input and action on issues heard in the state agency reports.

A discussion followed.

5. BUDGET REPORT – Shawn Fleming

The Council is on track with expenditures. Mr. Fleming discussed the handout regarding the breakdown of expenditures.

A discussion followed.

6. COMMITTEE REPORTS

A. ACT 378 SUB-COMMITTEE – Kay Marcel

The committee received reports from the state agencies that implement the Community and Family Support System. The Act 378 Cash Subsidy/Family Support survey has been developed and is ready to be mailed out. The survey will determine the benefits and impact of Cash Subsidy and Individual and Family Support services to the families receiving them. The results will be compiled in March. The Division of Administration and the Department of Health and Hospitals have discussed the possibility of eliminating the Cash Subsidy program due to lack of accountability and whether or not there should be means testing, so the survey is very important.

The Office for Citizens with Developmental Disabilities (OCDD) reported that the new screening instrument for the Cash Subsidy program has not been implemented statewide. It was piloted some time ago, and the policy has been revised, and it was ready to be promulgated but that has not happened. The committee recommends that the new screening instrument and policy be implemented without further delay.

The committee wondered whether a Memorandum of Understanding (MOU) with the districts/authorities would assure that Act 378 funds are spent and spent properly. The committee reviewed reports of variability among the regions and districts/authorities on how that money was spent. It was discovered that the MOU between DHH and the authorities/districts covers both Office of Behavioral Health (OBH) and OCDD services.

Regarding the supported living services administered by the Office of Aging and Adult Services (OAAS), the Arc of LA requested that all people served through that contract must apply for other funding that they may be eligible for (i.e. waiver or long term personal care services) and accept that funding when it becomes available to them. The committee agreed. There are 23 people currently being served on this contract and the application to any program they are eligible to receive should be made for them in the next 30 days.

The committee discussed and recommended changing the name of the OCDD and OBH Cash Subsidy program to “Family Flex Funds.” This name emphasizes that it supports families with children with disabilities and their numerous needs. A discussion followed.

B. SELF DETERMINATION/COMMUNITY INCLUSION/HOUSING - Olantha Scott

Ms. Scott reported the committee has several recommendations. One recommendation is for staff to research the availability and/or cost to buy videos of individuals with significant disabilities successfully included in schools and their communities, and the cost of conducting an educational campaign using these

videos to educate and change the attitude of targeted audiences, such as legislators, educators and civic clubs.

The committee recommends that the staff get a cost estimate to develop, print, and disseminate flyers that provide information on who parents should call when they discover their child has a disability.

Another recommendation is for the Council to pursue changing the name of the Cash Subsidy program to Family Flex Funds. The committee talked about the vulnerability of the cash subsidy program and the need to be proactive in advocacy efforts to save the program.

In the Council's monitoring of the Families Helping Families' contracts, the Council needs to ensure that the database of resources is kept updated and has an expansive list of resources. The Council should inquire how the Families Helping Families Centers outreach to the disability communities to ensure they are using efficient tools and strategies.

Regional rallies across the state have been planned for the week of March 12th through the 19th. Instead of having the rally at the State Capitol, regional planning committees are being formed and Council members are encouraged to participate. The theme of the rallies will be to preserve the capacity of the community that supports people with developmental disabilities.

People First is pursuing a contract with the Department of Education to implement a self advocacy curriculum and establish People First chapters in Louisiana public schools.

A discussion followed.

Ms. Beech referred to the three recommendations that came out of the Self Determination/Community Inclusion/Housing committee. The first recommendation is for staff to research the availability and cost of appropriate videos displaying people with significant disabilities successfully included in school and their communities, and the cost of an educational campaign for using those videos to educate and change attitudes of the targeted audience, such as legislators, educators, and civic groups. This research would be brought to the April planning meeting for consideration in the new Five Year plan.

Motion Passed. Motion for staff to research either videos that are already produced or the production of videos and the cost of an educational campaign made by Kay Marcel. Second by Donna Breaux. For – 11. Opposition – 1. Abstentions – 2.

The next committee recommendation is for staff to get a cost estimate to develop, print, and disseminate flyers that provide information of who parents can call when they learn their child has a disability.

A discussion followed.

Motion withdrawn. Motion to have staff get a cost estimate to develop, print and disseminate flyers that provide information on who to call if you have a child with a disability made by Kay Marcel. Second by Julia Kenny.

The third and final committee recommendation is for the Council to pursue changing the name of the Cash Subsidy program to the Family Flex Fund program.

Motion passed. Motion to pursue changing the name of the Cash Subsidy program to the Family Flex Fund program made by Val Hiser. Second by Chasedee Noto. Passed without objection.

C. HEALTH/EDUCATION/EMPLOYMENT – Pranab Choudhury

Mr. Choudhury presented the following list of recommendations made by the committee:

- Survey the Families Helping Families centers to determine how they are communicating with and the extent of the relationships they have with physicians and other health care providers and resources necessary to pilot an enhanced effort with connecting parents of young children with appropriate health care resources.
- Research models of developing students' "Social Capital" and skills that will utilize connections to get jobs.
- Research effective ways to teach children self advocacy skills and how to conduct self directed IEPs and access the extent these practices are currently used throughout the state
- Review the concept proposal for training transition specialists that was submitted last year.
- Research organizations in the other areas of the state interested in replicating the North Lake inclusive recreation program, university programs for recreation directors to determine the extent of inclusive recreation activities/programs and the feasibility of promoting these programs through institutes of higher education, research existing networks of inclusive recreation leagues, research the cost for sponsoring children in inclusive summer camps, and research the costs for recreation departments sponsoring inclusive socials for adults and dancing classes (i.e. Cajun, Zumba, etc.)
- Write a letter to the Board of Elementary and Secondary Education (BESE) expressing concerns over statements and omitted critical points contained in the draft Restraint/Seclusion Guidelines released by the Department of Education.

Ms. Beech mentioned that on each of these recommendations, the Council needs to be mindful of the Council's mandate. The three mandates are to advance capacity building, advocacy and system change.

Motion passed. Motion to conduct a brief survey with Families Helping Families centers to determine the extent of relationships they have with healthcare providers in their area and resources necessary to pilot an enhanced effort with connecting parents of children with appropriate health care resources made by Val Hiser. Second by Pranab Choudhury. Passed without objection.

Motion passed. Motion to research models of developing students' "Social Capital" and skills that will utilize connections to get jobs made by Pranab Choudhury. Second by Nanette Olivier. For – 18. Opposition – 1.

Motion failed. Motion to research effective ways to teach children self advocacy skills and how to conduct self directed IEPs and assess the extent these practices are currently used throughout the state made by Andrew Merlin. Second by Pranab.

Motion passed. Motion to review the concept proposal for training transition specialists that was submitted by the Arc-Baton Rouge last year made by Donna Breaux. Second by Sue Berry. Passed without objection.

Motion passed. Motion to accept the recommendation for the staff to research and survey inclusive recreation activities and recreation departments made by Mary Elizabeth Christian. Second by Olantha Scott. Passed without objection.

Motion passed. Motion to write a letter to BESE regarding concern over some of the language in the Restraints and Seclusion guidelines made by Donna Breaux. Second by Julia Kenny. Passed without objection.

Ms. Beech stated she had a recommendation. There are some Council members who have never gone through Partners in Policymaking. The state Ethics Law does not allow Council members to attend Partners if the contract pays their expenses. If one or two spots in the next Partners' class were reserved, the cost could be paid with Council member travel funds to avoid any conflict of interest.

Motion passed. Motion to use Council member travel funds to allow one or two Council members attend the 2012 Partners in Policymaking class made by Donna Breaux. Second by Chasedee Noto. Passed without objection.

7. STATE AGENCY REPORTS

A. DEPARTMENT OF EDUCATION (DOE) – Nanette Olivier

The reorganization of the Department of Education was formalized around the first week of August. What was formally the Division of Special Populations is now aligned to Louisiana's critical goals and the staff housed there are spread across various parts of the department. The three major goal offices are Literacy Section, Science, Technology, Engineering, and Math (STEM) Section and the College and Career Readiness Section.

There is a special education hotline to serve as a single point of contact for inquiries and informal complaints regarding special education. A database about these complaints will allow DOE to take formal action with identified issues.

Ms. Olivier recommended that a speaker from the DOE speak to the Council in the future about revamping exit documents from high school (career diplomas, G.E.D., industry based certification or state approved skills certification).

There is a departmental recognition of the correlation between the number of years that the child has been retained at an early grade level and its impact on dropout rate. The department will push for the districts to see that retention is not an intervention.

The Department of Education has a new website. There are still some kinks to be worked out and if Council members bump into them, let Ms. Olivier know.

A discussion followed.

8. COUNCIL MEMBER REPORTS

A. ADVOCACY CENTER (AC) – Lois Simpson

The Advocacy Center (AC) has written a proposal for a project to monitor up to 28 people in supported independent living. The AC visits some 5,000 people living in supported living situations every year. Many issues of neglect and abuse by the person providing these services come up particularly for people without family members.

The AC is looking for a source of funding for special education. Ms. Simpson feels a real deficit is that the AC does not have anybody in North Louisiana focusing on special education issues and the center has also had to cut back on the number of people monitoring institutions from developmental centers to child care facilities.

Due to people with disabilities having very few options for employment people end up going into sheltered workshops. Ms. Simpson feels this is a call to action beyond just reporting on the situation but advocating for a whole list of things that the AC would like done by the federal and state administrations.

The AC has a number of things in litigation including a suit against Jefferson Parish because its polling places are inaccessible. The judge has told Jefferson Parish to settle the case.

9. STATE OF THE STATE IN DHH - Kathy Kliebert, Deputy Secretary

Ms Kliebert spoke about issues that will influence the Department of Health and Hospitals (DHH) over the next several years regarding people with developmental disabilities. The National Health Care Reform is significant in many areas, but is especially in terms of the 500,000 people that will enter the Medicaid roles in 2014.

Then Medicaid will account for about 40 percent of everybody in the state. The other part of the health care reform is not just that people will have Medicaid coverage, but about 95 percent of the people in the state will have health coverage. A lot of the state funds that go to health care issues, public health care and behavioral health are going to be serving people that are not insured therefore those state funds will still be needed. There's going to be a requirement that if the insurance plan covers any type of acute illness, they also must cover behavioral health, both addiction services and mental health. The other big influence is the continuing decline of the budget due to decreases in federal match rate and revenues. There will be significant Medicaid shortages for next year. Finally, the administration's philosophy of moving people into home and community based services is very conducive to the Council's goals. The administration's philosophy is going to continue to move toward privatization.

A discussion followed.

10. COUNCIL MEMBER REPORTS CONTINUED

B. HUMAN DEVELOPMENT CENTER (HDC) - Phil Wilson

HDC received a grant from the U.S. Department of Education to do a post-secondary inclusive education project for kids in local high schools around greater New Orleans to attend Delgado Community College based on their person centered plan. HDC will provide training and support to the faculty at Delgado around universal design for learning.

11. STATE AGENCY REPORTS CONTINUED

B. OFFICE OF AGING AND ADULT SERVICES (OAAS) – Hugh Eley

Mr. Eley reported that the Community Choices (CC) waiver, which will replace the Elderly and Disabled Adult (EDA) waiver, was approved by Center for Medicare and Medicaid Services (CMS). The CC waiver has all the same services as the EDA waiver plus assistive devices, medical supplies, therapies, nursing, and respite care.

OAAS has been approved to start spending the additional funding for the Money Follows the Person grant. OAAS is trying to move people out of nursing facilities. About half of the waiver slots are going to people transitioning out.

A discussion followed.

C. BUREAU OF HEALTH SERVICES FINANCING (BHSF) – Don Gregory

Mr. Gregory stated that there was a typo in the numbers on the written report. He will follow up with staff that prepared the report and find out why it indicates more people are filled than allotted. When the report was prepared in December, BHSF

was in the middle of yet another round of rate reductions in Medicaid. He believes the staff were being a little bit pessimistic when they put something in the report about reductions. The DHH Secretary has announced that there will not be any further rate reductions in this fiscal year.

BHSF received a Children's Health Insurance Program Reauthorization Act (CHIPRA) grant award from the federal government for three and a half million dollars as recognition for achieving a 95 percent or more insurance rate for children in this state. That puts Louisiana in the top five states of the country for insuring children. The grant funds were used to mitigate rate cuts that had been proposed in December to outlier payments to hospitals, mostly for Neonatal Intensive Care Unit (NICU) services.

A discussion followed.

D. LOUISIANA REHABILITATION SERVICES (LRS) – Teresa Milner

LRS moved but can still be reached at the same phone number and same mailing address.

The Director position is vacant. Ms. Milner will send out information on the position to the Council in hopes that LRS can get a person that is passionate about serving people with disabilities.

When a person is determined eligible for services they are placed according to the severity of the functional limitations within five categories, from non-significant to most significant. People with the most significant disabilities are served in order selection group one. LRS is trying to keep that category open so they can continue to serve new applicants who meet the criteria for that category. LRS is working with the Louisiana Workforce Commission (LWC) to determine if any LWC programs can serve individuals on the waiting list.

The Louisiana Rehabilitation Council meetings are scheduled March 24-25, 2011 in Monroe and May 26-27, 2011 in Baton Rouge. The remainder of the meetings will be decided at the May meeting.

E. GOVERNOR'S OFFICE OF DISABILITY AFFAIRS (GODA) – Brandon Burris

Mr. Burris spoke briefly on the GOLD Awards announcing that over 250 people attended.

There have been staff changes in the office with GODA losing all assistants being reduced to a full-time staff of three people.

The Inclusive Art Show previously hosted by the Council will be February 23rd at the State Archives Building.

The Governor's Advisory Council on Disability Affairs (GACDA) was streamlined from 38 members, 21 of which were state agency representatives to 28 members with every person having a direct connection to someone with a disability or being an advocate.

The Statewide Independent Living Council, which Rocky Fuselier serves on, officially filed their annual report in December.

The Work Pays Group approached GODA about having the Governor sign an official Executive Order that the State of Louisiana hire individuals with disabilities and achieve a list of outcomes. Based upon financial resources at this time, the executive order was put aside. The Governor did issue a proclamation through the Work Pays Group identifying several key factors that the Work Pays Group had requested such as to declare the value of the individual with disabilities in the workforce and that they are underemployed. GODA is working with the Work Pays Group to develop work steps that will address these issues.

F. CHILDREN'S SPECIAL HEALTH SERVICES (CSHS) – Sue Berry

In October all of the co-pay services in Region One, Orleans Parish, were closed, including CSHS clinics at Children's Hospital. One hundred fifty (150) children receive some specialty services there. CSHS was able to transition all of those children successfully to private physicians who offer more access because they have clinic every day or at least once a week. CSHS retained an office suite at Children's for a family resource center, staffed with a social service counselor and a parent liaison from Families Helping Families.

A discussion followed.

G. OFFICE FOR CITIZENS WITH DEVELOPMENTAL DISABILITIES (OCDD) –Julia Kenny

The Greater New Orleans Resource Center focuses on health needs of individuals with developmental disabilities by working with physicians and teaching courses at LSU.

Ms. Kenny met with the Louisiana Health Care Quality Forum about OCDD preparing for 2014 so doctors are ready to accept individuals with intellectual disabilities and developmental disabilities regardless of their age.

The Children's Choice Waiver amendment is still at CMS.

The funding for Money Follows the Person was approved in December. The targeted populations have been broadened through 2016. OCDD can move 390 individuals residing in an ICF/DD or community home.

Children previously stuck in a NICU are now eligible through MFP which means children get home quicker. OCDD wants to reach out to public health to do parent training at home.

One thing OCDD is pulling back on a little bit is the electronic Individual Support Plan (ISP).

OCDD has been challenged this year with the all time high for crisis referrals of 532 individuals. Unfortunately, a lot of the individuals were not referred until they were at the breaking point. OCDD is working very closely with OBH and will develop a work group to implement a solution. Several meetings have been held with the Advocacy Center on the issues that are most concerning to people within the developmental centers and people in the forensic system.

Ms. Kenny indicated there are several work groups OCDD needs people for participation. She will forward the information to Ms. Winchell and Ms. Beech so they can send something out. One is Act 333, which is regarding family members providing services. A Question and Answer sheet on resource allocation was developed but people have indicated they now believe they cannot have a family member ever provide support and that is not the case. Ms. Kenny plans to add this information to the Q and A page.

A discussion followed.

12. UNFINISHED BUSINESS
None to discuss.

13. NEW BUSINESS
None to discuss.

13. PUBLIC COMMENT
None.

14. ANNOUNCEMENTS
The next quarterly Council meeting will be held April 20-21, 2011.

15. ADJOURNMENT OF MEETING

Motion passed. Motion to adjourn meeting made by Val Hiser. Second by Chasedee Noto. Passed without objection.