

**LOUISIANA DEVELOPMENTAL DISABILITIES COUNCIL
OCTOBER 20, 2011
MEETING SUMMARY**

Holiday Inn South
Baton Rouge, Louisiana

8:30 A.M.

GREETINGS AND INTRODUCTIONS

Sam Beech, Chair of the Council, welcomed everyone to the meeting. She stated there are forms on the table for anyone wishing 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.

MEMBERS PRESENT

Sam Beech
Donna Breaux
Brandon Burris, GODA
Lynn Cannon
Pranab Choudhury
Brenda Cosse'
Hugh Eley, OAAS
Rocky Fuselier
Reginald Garey
Don Gregory, BHSF
Julia Kenny, OCDD
Kay Marcel
Mark Martin, LRS
Heather Mobley
Chasedee Noto
Michelle Octave, GOEA
Nanette Olivier, DOE
Bambi Polotzola
Phil Wilson, HDC

MEMBERS ABSENT

Sue Berry, CSHS
Mary Elizabeth Christian
Laura Head
Val Hiser
Andrew Merlin
Olantha Scott
Lois Simpson, AC
Nicole Soileau
Stephen Yazbeck

STAFF PRESENT

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

GUESTS IN ATTENDANCE

Joseph Hicks for Sue Berry, CSHS
Frances Hilburn
Justin Ward, guest of Reginald Garey
Liz Gary, PIP Coordinator
Rebecca Ellis, LaCAN Coordinator, Region IX
Maria Villafranco, guest of Lynn Cannon
Johniece Whitehead
Stephanie Patrick for Lois Simpson, AC
James Sprinkle, FHF at the Crossroads
Lynette Fontenot
Dora Chandler
Stephanie Mire, Transcriptionist

SUMMARY OF JULY MEETING

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

Motion passed. Motion to accept the July summary made by Nanette Olivier. Second by Lynn Cannon. Passed without objection.

CHAIRPERSON'S REPORT –Sam Beech

On July 25th through 27th Shawn Fleming and Ms. Beech participated in the Administration on Developmental Disabilities Technical Assistance Institute in Washington, D.C. The Institute emphasized Council effectiveness and accountability, and Employment First initiatives. While in Washington, they visited Senators Vitter and Landrieu and Congressmen Fleming and Alexander to discuss the institutional bias of Medicaid and the need for more funding for home and community based services.

On August 13th, Ms. Beech participated in the LaTEACH training in Lake Charles.

Ms. Beech sent a letter on behalf of the Council to the Board of Elementary and Secondary Education (BESE) regarding graduation requirements, End Of Course (EOC) tests, Louisiana Alternate Assessment 2 (LAA2) and requesting that BESE allow the Special Education Advisory Committee (SEAC) to establish their agenda and review any policies related to students with disabilities. BESE subsequently voted on rule changes regarding graduation requirements and SEAC in line with the Council's recommendations.

On August 18th, Sandee Winchell, Kay Marcel, and Ms. Beech met with Julia Kenny and Kathy Kliebert to discuss the New Opportunities Waiver (NOW) Trust Fund proposal and Means Testing for Flexible Family Funds. No agreement was reached on Means Testing but consensus reached on the NOW Trust Fund formed the basis of the proposal later approved by Secretary Greenstein during the meeting on October 10th.

Ms. Beech has been participating in the Act 299 Support Coordination Workgroup.

On August 3rd, Ms. Beech participated in leadership training with Ms. Winchell, Ms. Marcel, Bambi Polotzola and Mr. Fleming. Council staff developed training for the new Chairs of Council committees in basic parliamentary procedure.

On August 10th, Ms. Beech participated in the LaTEACH/LaCAN Kick-off. Potential advocacy issues to target were discussed.

Executive Committee

The Executive Committee met and discussed the committee structure and selection process. It was decided that new members will still have the option of choosing which committee to serve on, but staff and Ms. Beech will review committee composition and how many parents, self advocates and state agency representatives serve on each committee. Members may be asked to change the committee they serve on to balance the committees.

Due to the primary and general election, new legislators being elected and early start of the legislative session, it would make it difficult to schedule round tables and rallies. The Executive Committee recommends allowing each region to have flexibility in holding additional round tables, an educational event or a nicer, bigger round table instead of a regional rally. Each region would have \$500 of "Rally Funds" to support these events.

Ms. Beech reminded Council members to report policy changes made by disability groups they served on.

Orientation for new Council members and members who received the abbreviated orientation will be held in January.

The last thing discussed was the concern of effectiveness of the Council and Council meetings. An ad hoc committee will be created to review the structure of Council and committee meetings and recommend changes to increase participation and effectiveness. Ms. Marcel, Donna Breaux, Nanette Olivier and Mark Martin volunteered to serve on the ad hoc committee.

Motion passed. Motion to give each region \$500 to fund additional or expanded round tables or educational events in lieu of regional rallies made by Chasedee Noto. Second by Lynn Cannon. Passed without objection and one abstention.

The next item to be voted on is the proposed 2012 Council Advocacy Agenda:

- Money Follows the Person
- Appropriation for 200 NOW slots
- Equitable inclusion and services to students with disabilities in charter schools
- Continued monitoring of:
 - high school redesign and graduation requirements
 - value added performance based teacher evaluation and
 - restraint and seclusion practices.

Motion passed. Motion to accept the 2012 Council Advocacy Agenda made by Lynn Cannon. Second by Kay Marcel. Passed without objection and two abstentions.

Ms. Beech presented Certificates of Participation to Lynn Cannon and Heather Mobley for their four years of service on the Council.

EXECUTIVE DIRECTOR'S REPORT – Sandee Winchell

On October 10th, DHH Secretary Greenstein approved the Council's NOW Trust Fund proposal. The proposal provides for every \$66,000 of state general fund dollars deposited into or unencumbered in the trust fund, one NOW slot will be phased in. This amount of money will pay for the slot, including acute care costs, for 3 years. Unencumbered monies in the fund shall remain in the fund and cannot be used to pay for anything else. For example, if \$50 million is deposited one year, \$66,000 per slot for 500 slots only costs about \$30 million, there will be about \$20 million left. That \$20 million has to stay in the fund so new slots can be

funded the following year. The proposal also includes a provision when there are no funds deposited into the trust fund, DHH will include 200 new NOW slots in their budget request. Since it is not guaranteed that the Division of Administration or the legislature will provide the funding for those slots, advocating for those funds is included on the Council Advocacy Agenda.

Secretary Greenstein also responded favorably to the Council's Money Follows the Person proposal and the discussion of that issue. DHH is currently considering that proposal. Council members received a handout of the information presented to Secretary Greenstein. Louisiana has the highest number of people in all ICFs/DD per capita in the country. The Council believes that many people who are currently in private facilities can be served at less cost in waiver services and believes the right thing to do is to give people the option to live in their own homes.

Ms. Winchell encouraged Council members to attend one of the Family Forums on Individual and Family Support in their area the Council is co-hosting with the Office for Citizens with Developmental Disabilities (OCDD). Mark Thomas and others from OCDD were commended for being welcoming to families and encouraging comments on the program.

OCDD is hosting Employment First listening sessions and Council members were encouraged to participate in the one in their region.

The Alliance for Full Participation will take place outside of Washington D.C. in November. The Council dedicated \$8,000 for the national and state participation in the Employment First initiative. Individuals who are employed or wishing to be employed and parents of adults who are employed or wishing to be employed were selected to attend this national summit on employment. Donna Spears, a self advocate from Jennings, Chasedee Noto, Mylinda Elliott, a parent from Lake Charles, Carol Calix, the director of Families Helping Families in New Orleans and also a parent, Ms. Beech and Ms. Winchell will be attending. There will be state team meetings during the Summit. Ms. Kenny along with some of her staff and Phil Wilson are attending also.

Families Helping Families has always been included in the LaCAN/LaTEACH Kick off. This year People First joined the Kick Off. The Council asked them to pay for two Advocacy Facilitators with unused funds in their contract. The Advocacy Facilitators will serve in two regions of the state to build the advocacy movement within People First, build a bridge between People First and LaCAN and LaTEACH and motivate People First members to be more involved in grassroots advocacy.

Mr. Fleming wrote an article that was published in the Association of Professional Behavior Analyst Reporter on the rules BESE adopted allowing behavior analysts to be employed in Louisiana schools.

BUDGET REPORT – Shawn Fleming

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

COMMITTEE REPORTS

➤ HEALTH/EDUCATION/EMPLOYMENT COMMITTEE – Bambi Polotzola

The Health/Education/Employment committee reviewed two concept proposals. The committee felt the one submitted by Gulf Coast Market Place does not fit within the Council's scope and mandate.

The second proposal was from Century Mode Play Group for toddlers with autism and related disabilities. The committee decided not to recommend this proposal because of concerns regarding a lack of ability to replicate, the bulk of funds went to tuition for students and it didn't meet the Council's mandate.

Council staff created a spreadsheet as a planning tool for the committee to use to develop the Five Year Plan with the goals and objectives and be able to forecast and think about what to do five years into the future to get to the ultimate goals.

The committee also discussed Louisiana Rehabilitation Services (LRS) and how Louisiana does not spend a large amount of the federal grant. One objective in the Plan is to fully draw down the money for LRS. The total basic support grant for LRS is \$54,275,934 for federal fiscal year 2012. That would require a total state match of \$14,689,675. Currently, there is only \$8,205,062 of state funds, so an additional \$6.4 million in state general funds is required to draw down \$50 million in federal funds. Nanette Olivier, Mark Martin, Ms. Beech, and Ms. Noto volunteered to serve on an ad-hoc committee to discuss strategies to address the federal draw down problems being experienced by LRS.

Other advocacy issues the H/E/E Committee feels are important:

- People who work in sheltered workshops or other places that are shut down without having alternate options that enable them to be integrated into the community.
- The Education Advocacy Agenda includes:
 - Rules and outlines for use of restraint and seclusion
 - Graduation requirements, specifically changes regarding End Of Course testing and the LAA2
 - The BESE Advisory Council and Special Education Advisory Council being moved out from under complete control of BESE.

The last thing discussed was the Childcare Initiative contract going directly to the Arc of Baton Rouge instead of the Department of Children and Family Services (DCFS).

➤ SELF DETERMINATION/COMMUNITY INCLUSION/HOUSING COMMITTEE – Phil Wilson

The Advocacy Center submitted a concept proposal to establish an Ombudsman program for people with developmental disabilities living in their own homes in the community. The committee recommends the Council further investigate developing this pilot program.

The second concept proposal was submitted by LATAN regarding information outreach and training demonstration in a couple of regions of the state. The committee recommends the Council further investigate making a pilot available in one region of the state that focuses on assessment using assistive devices in natural settings in the community. In addition to having a focus on assessment in natural settings, the committee would like to make sure the pilot would include information and referral of potential ways to either fund or procure those devices.

Also discussed was an overview of the Home and Community Based Services Improvement Plan (Act 299), a report on the Money Follows the Person (MFP) grant and legislative proposal and an update on People First.

Motion passed. Motion for Council staff to do more research on the concept proposal submitted by the Advocacy Center regarding an Ombudsman program for people in supported living made by Chasedee Noto. Second by Pranab Choudhury. Passed without objection.

Motion passed. Motion for Council staff to do more research on conducting assistive technology assessments in natural settings made by Kay Marcel. Second by Nanette Olivier. Passed without objection.

Ms. Beech presented Ms. Marcel with a Lynette Fontenot original print for her 22 years of volunteer service as the LaCAN Statewide Coordinator and expressed the Council's appreciation for her leadership and dedication.

➤ ACT 378 SUB-COMMITTEE – Sam Beech

It was brought to the attention of the committee that the Districts and Authorities get Act 378 funds that flow directly to them and not through OCDD, therefore the Council will write a letter to Ms. Kenny and the Districts and Authorities requesting them to submit their data to OCDD so it can be included in OCDD's Act 378 report for the Act 378 committee to review.

OCDD has corrective action plans for the South Central Louisiana Human Services Authority (formerly Region 3) and the Region 6 OCDD office regarding all of their Individual and Family Support funds not being spent.

The Flexible Family Fund rule has been adopted into the Louisiana Register. The rule changed the name from Cash Subsidy to the Flexible Family Fund and put into place new assessment procedures for eligibility determination. OCDD will contact all recipients to inform them of the changes and that they will be required to meet annual eligibility. The

name and rule changes also apply to program recipients in the Office of Behavioral Health.

➤ MEMBERSHIP COMMITTEE – Rocky Fuselier

The membership committee of Brandon Burris, Donna Breaux, Ms. Marcel, and Mr. Fuselier reviewed applications from five self-advocates and seven parents. Although the Council is losing two parents and one self-advocate, the committee made the decision to select two self-advocates and one parent to have a stronger self-advocate voice on the Council. The committee was unable to select anyone from Region 6, so this position was filled by someone in Region 7. The membership committee is recommending Deshae Lott- Sadow, a self-advocate from Bossier City, Erin Smith, a self-advocate from Springhill and Patsy White, a parent from Luling to be submitted to the Governor for appointment on the Council.

Motion passed. Motion to accept the recommendations of the Membership Committee of Deshae Lott-Sadow, Erin Smith and Patsy White made by Mark Martin. Second by Donna Breaux. Passed without objection.

COUNCIL MEMBER REPORTS

➤ HUMAN DEVELOPMENT CENTER (HDC) – Phil Wilson

Dr. Wilson thanked everyone who assisted with the Louisiana Consortium for Employment Systems Change grant application.

The Human Development Center is negotiating with contractors who bid on their new building with the hopes to have a new facility completed within the next two to three years.

HDC's pilot program called the Post Secondary Education for All (PEAC) is supporting students with intellectual disabilities enrolled at Delgado Community College. The students are doing great and have become a part of the campus, developing friendships and contributing. One participant is fluent in Vietnamese and has been helpful with a number of other students who have English as their second language. Relationships and positive change are occurring within Delgado's Office for Disability Services. Some issues with transportation for each student have improved but there continue to be challenges with arranging transportation. Another issue was the scheduling of training on Universal Design for Learning and some issues with the Delgado faculty. A lesson learned is the need to work more with the instructors to help them support the students without having different expectations.

A discussion followed.

➤ ADVOCACY CENTER (AC) – Stephanie Patrick for Lois Simpson

The AC was contacted in March by a parent whose child had been taken off the waiver services waiting list because the mom hadn't returned the right form. Even though OCDD and Medicaid had the parents' right address, this form was sent to the wrong address. The

AC managed to get the child back on to the waiting list but found that approximately 1,991 people had been taken off the list since April 2010 because the form was not returned. The AC worked with OCDD to get this corrected for those individuals.

It was also discovered that there were issues with people who had been given a waiver slot but hadn't returned their 90L form in time. Since they hadn't returned it in time they were taken off the list and were not going to get services. The AC was able to work with OCDD to get these individuals the opportunity to get their waiver services. The AC is monitoring to be sure all the people waiting get the notices needed and return forms so they don't lose their slots.

There was an issue that people in nursing homes could have much more income than people who were getting waiver services and be eligible for Medicaid. Louisiana is the first state to make income requirements the same for people in a nursing home and people getting services at home.

The AC is monitoring the Coordinated System of Care/Louisiana Behavioral Health Partnership changes and wants to know if people are having problems making choices or getting information in accessible formats.

The AC continues to identify and address systems issues in special education and wants to hear input from the community if there are things that are not being done.

A discussion followed.

STATE AGENCY REPORTS

➤ GOVERNOR'S OFFICE OF ELDERLY AFFAIRS (GOEA) – Michelle Octave

The Governor's Office of Elderly Affairs wants to continue to work with the Council in getting the information out on the Aging and Disability Resource Center (ADRC) and how it serves as a clearing house for a variety of long-term care options in which individuals all ages can call to receive assistance.

➤ LOUISIANA REHABILITATION SERVICES (LRS) – Mark Martin

Mr. Martin stated that getting LRS fully funded and drawing down federal funds is his number one goal as the Director. He indicated the way to accomplish this is to have a lot of people testify at the legislature.

LRS hired Eddie Gibbons as a Program Manager. Mr. Gibbons is a former Regional Manager with the Department of Vocational Rehabilitation in Mississippi. Mr. Brian Moore is the new Office of Workforce Development Director.

The Rehabilitation Services Administration (RSA) approved LRS' State Plan for 2012. LRS had been on a two year performance improvement plan. As of September 30, 2011 LRS

was removed from the improvement plan since it met the necessary performance indicators.

A discussion followed.

➤ DEPARTMENT OF EDUCATION (DOE) – Nanette Olivier

Ms. Olivier highlighted the following items in her report:

The Louisiana Assistive Technology Centers work with school systems and provide technical assistance for specific children.

Louisiana is a recipient of the Striding Readers Comprehensive Literacy (SCRL) Grant that provides \$28.5 million for the first year and up to \$142.4 million over 5 years. A different feature about this project is that it goes from birth to 12th grade.

The DOE also received funding for the State Improvement Grant for around \$6 million. There is a new transition website at the Department of Education. The URL is <http://transition.DOE.Louisiana.gov>.

A discussion followed.

➤ CHILDREN'S SPECIAL HEALTH SERVICES (CSHS) – Joseph Hicks for Susan Berry

Clayton Williams left the Office of Public Health. J.T. Lane, previously Chief of Staff, will serve as Interim Assistant Secretary. Courtney Phillips will fill in as Interim Chief of Staff.

One of the programs under CSHS, Early Hearing Detection and Intervention, has updated its website. There are several links with resources for parents, professionals and stakeholders.

The staff is continuing to participate in the Early Childhood Hearing Outreach (ECHO) initiative. This is sponsored by the National Center for Hearing Assessment at Utah State. The ECHO initiative focuses on hearing deficits that show up later in life between 0 and 3 years old.

A discussion followed.

COORDINATED SYSTEMS OF CARE (CSOC) – Jody Levison-Johnson, Director

Dr. Levison-Johnson presented on the Coordinated Systems of Care in Louisiana.

STATE AGENCY REPORTS CONTINUED

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

Ms. Kenny discussed initiatives around supporting people who do not fall within either service delivery system. It must be determined if it is a mental health disorder or behavioral health disorder and how DD wraps around that.

She clarified a few things with the Advocacy Center report this morning. OCDD is in the process of validating the waiting list by sending out two certified letters and cross checking with SRI (contractor that maintains the waiting list). They have even sent out three certified letters. OCDD also has a contract with the Arc of Louisiana and People First to follow up with phone calls to try to track people down. Unfortunately, what happened this year is children were put into that soft category (i.e. inactive). Medicaid wasn't identifying them. Now when the validation happens there will be a notification if OCDD can't find the child and they will stay in the active category. Another change is at the 60 day mark new Waiver recipients are flagged and get a support coordinator.

Early Steps has been reauthorized for the Part C program. OCDD will make sure that families and stakeholders have an opportunity to review what the changes are and to assist OCDD in remarks sent to the federal government regarding those changes. OCDD is experiencing a lot of success in the Money Follows the Person grant. One thing the Centers for Medicare and Medicaid Services (CMS) are excited about is the direct support service staff training. A lot of agencies have requested positive behavioral supports training. It is hoped this will help with crisis referrals.

Two community organizations applied to work with OCDD on transitioning individuals out of developmental centers. Pinecrest was targeted because that's where most people are, and that's where the greatest number of transitions is coming from.

As of September, OCDD has about 76 people transitioned from ICFs/DD into the NOW and nine children from nursing home facilities into Children's Choice. The Residential Options Waiver (ROW) is allowing children to go home or into a foster situation from nursing homes or hospitals. There are eleven more children preparing to be discharged from a nursing home through the ROW. Things not paid for by Medicaid, such as durable medical equipment, a ventilator, or intensive family training for families with children with these significant medical needs are covered by this demonstration grant.

OCDD and the Office of Aging and Adult Services (OAAS) had an October 1st implementation date of the Support Coordination Monitoring Tool. Both agencies can offer technical assistance to make sure there is adequate training for support coordinators and providers.

The ROW is really not functioning the way it was intended. A workgroup will meet in mid November that's comprised of OCDD staff, Medicaid rate methodology folks, and providers to look at why the methodology is not working for community conversion.

OCDD is partnering with Dr. Levison-Johnson through the Coordinated System of Care and the Louisiana Partnership for Behavioral Health to get wrap around services for people who have Access One Personality Disorder which isn't recognized by Behavioral Health.

Dr. Wilson, Donna Spears and Ms. Kenny are sitting on a panel at the Alliance for Full Participation Summit in November. Ms. Kenny will be doing breakfast round tables to develop positive dialogue around systems change and how to move providers from sheltered employment into other types of employment options.

A discussion followed.

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

One of the three areas of focus in the Systems Transformation grant was quality improvement. A series of stakeholder meetings were held to identify quality measures performance indicators that would be used across all waiver programs in both OCDD and OAAS. The Support Coordination model came out of that grant. The other big change is it takes regional offices in both OAAS and OCDD out of the business of being a monitor for support coordination. The focus now is to give the training to support coordinators, support coordination supervisors and support coordination agency management so that they understand these are the things being measured going forward.

All the support coordinators have been retrained and certified in the plan and assessment process. The support coordinator will do an assessment and plan of care. It is then reviewed in-house according to criteria developed then sent directly to SRI to be approved for services. The hope is that this will cut a month or more off the top of somebody getting waiver services delivered.

OAAS is trying to get initial money through the legislature for the state-funded PCA program they took over from the Department of Children and Family Services through the Arc of Louisiana.

As of October 1st, OAAS is the administrative agency office of DHH running the permanent supportive housing program. This program started as part of the Road Home recovery after Katrina. It has been recognized now by Housing and Urban Development (HUD), CMS and several others as being a best practice across the country as an effort to get people with disabilities, primarily behavioral health issues, off the street, out of emergency rooms, out of mental hospitals and into an apartment to help them be more integrated in the community and in a stabilized kind of situation. OAAS is able to get 3,000 apartment units. It's the first program in the country that is for the elderly, people with developmental disabilities, behavioral health needs, and physical disabilities.

A discussion followed.

➤ BUREAU OF HEALTH SERVICES FINANCING (BHSF) – Don Gregory

On October 14th, about 300 advocates came together to discuss the behavioral health partnership initiative and the managed care initiative on the acute care side. It was equally balanced between acute care and behavioral healthcare.

Between now and June 1st BHSF will move a little more than 900,000 Medicaid recipients from the fee-for-service model to managed-care model for acute care. On March 1st a significant population will be moved into the new coordinated health model that is bigger than Medicaid. It is important to realize that for behavioral health models there will be populations and services outside of Medicaid that will be provided and served through the initiative. Currently 26%, one in four citizens of the state population is on Medicaid. By 2014 this is expected to increase to somewhere around 46%. Medicaid already is a significant payer of healthcare services in the state and it will be the dominant payer in about three years. Medicaid is changing so the conversation to this Council in regard to Medicaid is certainly going to be critical over the next three years as it moves into national healthcare reform.

A discussion followed.

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

Mr. Burris stated the Governor's Advisory Council on Disability Affairs (GACDA) has openings and asked the Council for recommendations.

The Governor's Disability Awards Ceremony will be held on December 13th.

GODA is working with the DOE to make the Inclusive Art Contest more inclusive this year and have specifically targeted special education programs across the state.

Due to changes to the Americans with Disabilities Act (ADA) laws that happened last legislative session in the state and on a federal level, GODA is having a one day symposium and partnering with the state Fire Marshal's Office and the Arc of Louisiana.

A discussion followed.

UNFINISHED BUSINESS

None to discuss.

NEW BUSINESS

Brenda Cosse' expressed a concern about the closed captioning of the live stream during BESE meetings not working. Mr. Burris stated there is a piece of legislation that requires BESE to provide it. Ms. Olivier stated she would look into it and email Ms. Winchell her findings.

ANNOUNCEMENTS

Ms. Noto recommended a book on cyber bullying for preteens and teens.

The next Council meeting is January 18th and 19th. Orientation will begin January 17th in the afternoon.

Adjournment of Business Meeting

Motion passed. Motion to adjourn made by Lynn Cannon. Second by Brenda Cosse'. Passed without objection.