

**LOUISIANA DEVELOPMENTAL DISABILITIES COUNCIL
JANUARY 16, 2014
MEETING SUMMARY**

8:30 A.M.

Embassy Suites
Baton Rouge, LA

MEMBERS PRESENT

Sam Beech
Sue Berry, OPH/CSHS
Donna Breaux
Vickie Davis
Rocky Fuselier
Reginald Garey
Kristopher Hebert
Mark Martin, LRS
Terry McFillen
Paula Moreau
Chasedee Noto
Bambi Polotzola
Lou Ann Owen, BHSF
Stephanie Patrick, AC
Deshae Lott Sadow
Erin Smith
Patsy White
Phil Wilson, HDC

STAFF PRESENT

Shawn Fleming
Paige Freeman
Robbie Gray
Brandi Jones
Keokah Sanders
Derek White
Sandee Winchell

MEMBERS ABSENT

Brenda Cosse'
Hugh Eley, OAAS
Kay Marcel
Stephen Osborn, DOE
Allison Rouse
Monica Simmons

GUESTS PRESENT

Alice Blundell, guest of Deshae Lott Sadow
Jeff Sadow, guest of Deshae Lott Sadow
Bonnie Buckelew
Wesley Cagle, South Central Louisiana Human Services District
Donnica Conway
Cindy Deshotel, guest of Donna Spears
Jason Durham
Rebecca Ellis, Northshore FHF
Lynsey Hebert, Transcriptionist
Michelle Hurst
Kristen Kliebert, OAAS
Ellis Roussel, GODA
Donna Spears
Mark Thomas, OCDD

SUMMARY OF OCTOBER MEETING

Patsy White served as acting Chairperson and called the meeting to order. Ms. White requested a motion to accept the summary from the October meeting.

Motion passed. Motion to accept the summary of the October Council meeting made by Donna Breaux, seconded by Phil Wilson, passed without objection.

CHAIRPERSON'S REPORT – Patsy White for Kay Marcel

Ms. Marcel attended and served as Mistress of Ceremonies for the Advocacy Leadership Conference on October 29th. The conference was very well attended and very well received by all participants.

Ms. Marcel appointed the following members to a Planning Ad Hoc committee to draft amendments to the Council's Five Year Plan: Bambi Polotzola, Brenda Cosse', Chasedee Noto, Deshae Lott Sadow, Kris Hebert, Mark Thomas, Mark Martin and Patsy White. Ms. Marcel will also serve on the committee. The committee will meet on February 6th and, if necessary, have a second meeting on February 25th. Recommended amendments from this Committee will be presented to the full Council during the April planning meeting.

Ms. Marcel and Sandee Winchell are members of the OCDD System Transformation Core Stakeholder Group. This group meets monthly and has been considering changes to the waiver waiting list, assessing the level/urgency of need of people on the waiting list, the process used in eligibility determination/redetermination, and changing eligibility criteria for waiver and ICF/DD services.

Ms. Marcel, Bambi Polotzola, Terry McFillen, Ms. Winchell and the Region 4 LaCAN Leader, Darla Louviere, met with Senator Fred Mills on January 6th to discuss the Council Legislative agenda, particularly a proposal to reduce the negative impact of Act 439 on services and supports for people with disabilities and other vulnerable populations.

The Executive Committee met on October 29th and approved a request by Ms. White for a stipend of \$695 to attend the National Prader Willi Syndrome Association conference. The balance in the stipend fund is \$2305.

EXECUTIVE DIRECTOR'S REPORT – Sandee Winchell

Ms. Winchell welcomed Bonnie Buckelew, Donnica Conway, Michelle Hurst and Donna Spears to the meeting as pending Council members.

Ms. Winchell announced that Lilian Wise resigned from the Council creating an opening in Region nine. Ms. Winchell requested consideration of the Membership Committee's recommended candidate to be submitted to the Governor without a full Council vote.

MOTION PASSED. Motion to allow the Membership Committee to choose a replacement for Lilian Wise and have the person's name submitted to the Governor without a full Council vote made by Kristopher Hebert, seconded by Deshae Lott Sadow, passed without objection.

Ms. Winchell and Ms. Marcel met with Department of Health and Hospitals (DHH) Secretary Kathy Kliebert and OCDD Interim Assistant Secretary Mark Thomas to discuss:

- The burden for people self-directing their waiver services to meet the rigorous training requirements for medication administration.
 - Ms. Kliebert and Mr. Thomas hope to reach consensus with the Nursing Board and pursue legislation to exempt people in self direction from the medication administration requirements.
- The continued lack of information on providers available to waiver recipients. A year ago the Council recommended including provider information and data online.
 - The System Transformation plan includes some improvements to the Freedom of Choice process which will include the sharing of provider data. Secretary Kliebert said DHH has data that could be posted prior to the April meeting. The Council will assist in identifying a graduate intern to assist OCDD in collecting and collating the data.
- Amending the Supports Waiver by removing the individual caps on services to make it more flexible.
 - Mr. Thomas indicated the System Transformation Plan includes this plan but Secretary Kliebert indicated they would make changes now. The System Transformation Core Group will be asked to prioritize which aspects should be implemented first.
- Ms. Winchell provided DHH a list of ongoing Council concerns regarding recommendations and/or issues that have been discussed in the quarterly meetings with little or no change occurring.
 - Secretary Kliebert said they would provide an update at each quarterly meeting.
- Council's Legislative Agenda
 - Discussed every DHH related issue on the Council's Advocacy Agenda. Regarding additional waiver slots, DHH requested funding for 200 additional New Opportunities Waiver slots and to fill all existing slots.
- DHH's Legislative Agenda:
 - Change eligibility and expand criteria for the Traumatic Brain Injury and Spinal Cord (TBISC) Trust Fund.
 - Combine the Community and Family Support program with the state funded Personal Assistance Services program to increase flexibility for all participants.

- Technical bill to reflect current practice of which state office receives complaints and handles appeals.
- Tentative: Exemptions for people in self direction from medication administration training requirements.

Ms. Winchell asked the Council to consider taking a position on the DHH legislative agenda at the following priority levels: Priority level one typically involves grassroots advocacy alerts; priority level two issues are addressed through Council members and/or staff advocacy efforts; and priority level three issues are merely tracked without action. It is recommended that the TBISC Trust Fund and the State Personal Assistance Services issues be considered a priority level two; exemption of self-direction recipients from the med administration requirements be a priority level one; and the technical bill regarding complaints and appeals be a priority level three.

MOTION PASSED. Motion to support DHH's proposed 2014 Legislative issues: changes to eligibility for the TBISC Trust Fund and the State Personal Assistance Services at a priority level two; exemption of self-direction from the medical administration requirements at a priority level one; and a technical issue regarding which agency receives complaints and handles appeals as a priority level three made by Deshae Lott Sadow, seconded by Kristopher Hebert, passed without objection. Mark Martin, Stephanie Patrick and Bambi Polotzola abstained.

The Council collaborated with People First and other advocacy agencies to change language in Statute to reflect people-first language. This would be listed as a Priority Level 2.

MOTION PASSED. Motion to support people-first language in Statutes made by Bambi Polotzola, seconded by Kristopher Hebert, passed without objection. Chasedee Noto abstained.

Ms. Winchell requested authority for her to take, express or revise Council positions on issues presented in bills throughout the legislative session when it is not feasible to convene the Executive Committee.

MOTION PASSED. Motion to grant the Executive Director and Deputy Director, in her absence, the authority to take, revise, and communicate the Council's position on issues presented in legislation when such decisions have to be made prior to Council and/or Executive Committee vote provided all such decisions shall be aligned with the Council's mission and values made by Deshae Lott Sadow, seconded by Donna Breaux, passed without objection.

Council members were encouraged to participate in the upcoming Legislative Roundtables and the Statewide Rally on March 19th.

Ms. Winchell reminded Council members the DHH website has a section on Managed Long-Term Supports and Services where comments can be submitted. The email address is longtermcare@la.gov.

Ms. Winchell informed Council members to submit any comments regarding the Systems Transformation group directly to OCDD.

BUDGET REPORT – Shawn Fleming

Mr. Fleming shared the Council expenditures through December 2013.

COMMITTEE REPORTS

ACT 378 SUB-COMMITTEE - Sam Beech

The committee decided to not recommend the Council request additional funding for Flexible Family Funds from the Legislature.

The committee decided to ask each Human Services District and Authority for the number of requests for Individual and Family Support, the number of requests that received funding, and the number of each recipient by priority level.

The committee recommended for the Council to support the expansion of State Personal Assistance Services by including a wider variety of services, merging it with the Community and Family Support Program, and aligning eligibility in both programs.

The committee recommended Council leadership meet with Dr. Dunham, the Assistant Secretary of the Office of Behavioral Health (OBH), to discuss creating a policy regarding eligibility and use of Consumer Care Resources and for this policy to be referenced in the Memorandum of Understanding between DHH and the Human Services Districts and Authorities.

MOTION PASSED. Motion for Council leadership to meet with Dr. Dunham, Assistant Secretary of the Office of Behavioral Health (OBH), to discuss creating a statewide policy regarding eligibility and use of the Consumer Care Resources and reference this policy in the Memorandum of Understanding that DHH has with the Human Services Districts and Authorities made by Kristopher Hebert, seconded by Erin Smith, passed without objection.

MEMBERSHIP COMMITTEE – Rocky Fuselier

The membership committee was composed of Brenda Cosse', Sam Beech, Brandon Burris, Patsy White and Mr. Fuselier. The committee met twice. The committee recommends the following people be submitted to the Governor for appointment: Bonnie Buckelew, Donna Spears, and Donnica Conway. As alternatives, the committee selected Shannon Woodside and Geneva Wareham as first and second alternate for the parent representative, respectively, and Gwen Houston and Enrice Jones as the first and second alternate for the nonprofit representative, respectively. Michelle Hurst was selected by the committee and submitted to the Governor under authority the Council granted at the October meeting.

MOTION PASSED. Motion to accept the recommendation of the Membership Committee to submit Bonnie Buckelew, Donna Spears, and Donnica Conway to the Governor for Council membership. And to accept Shannon Woodside, Geneva Wareham, Gwen Houston, and Enrice Jones as alternates made by Kristopher Hebert, seconded by Deshae Lott Sadow, passed without objection.

**SELF DETERMINATION/COMMUNITY INCLUSION/HOUSING COMMITTEE –
Deshae Lott Sadow**

The Committee developed suggestions for alternate ways to support People First including: asking self-advocates what they need to be successfully involved in systems change; mentoring with leadership and support in goal setting; involvement in local advocacy efforts; and seeking information from other DD Councils in how self-advocacy groups are supported other than financial.

The committee recommends creating an Ad Hoc committee to develop options regarding Partners in Policymaking participant recruitment, engaging graduates, and continuing and/or changing the program.

The Committee requested that staff collect data on students at the Louisiana Special Education Center to determine whether Council advocacy is needed for the school systems in the areas of the children's origins to offer the supports needed without removing children from their homes and communities.

The final request is for Council staff to develop an informational sheet instead of a position paper or fact sheet on Natural Supports.

MOTION PASSED. Motion for staff to develop an informational sheet on Natural Supports made by Sam Beech, seconded by Donna Breaux, passed without objection.

MOTION PASSED. Motion to form an Ad Hoc Committee to consider options for the Partners in Policymaking initiative made by Donna Breaux, seconded by Phil Wilson, passed without objection.

HEALTH/EDUCATION/EMPLOYMENT COMMITTEE – Patsy White

The committee requested that staff try and determine if there has been a change in the number of physicians, by specialty, accepting Medicaid since implementation of the Affordable Care Act.

The committee requested additional information on the Affordable Care Act, specifically, another presentation on the ACA and any research comparing Canada's health insurance system to the Affordable Care Act.

The Committee recommends the Council consider convening an Ad Hoc Committee to consider alternate formats for Council meetings that would be guided by a vision for systems change across agencies.

MOTION PASSED. Motion to form an ad-hoc committee to develop recommendations for changing the Council meeting format that will be guided by a vision for systems change across agencies made by Sam Beech, seconded by Vickie Davis, passed without objection.

The Department of Education changed its policy and will reinstate the textbook adoption committee as was recommended by the HEE Committee in October. Information was provided about implementation of Common Core State Standards implementation for teachers of students with disabilities.

COUNCIL MEMBER REPORTS

Ms. White shared information from her participation at the Prader-Willi Syndrome National Conference in Sarasota, Florida in November. Bambi Polotzola shared information from her participation at the Individuals with Disabilities Education Act (IDEA) Leadership Conference in Washington, DC in July.

LEGISLATIVE VISITS BY MEMBERS

Ms. Polotzola reported on meetings with Senator Fred Mills, Representative Nancy Landry, Representative Mike Huval, and Representative Bernard LeBas. Each Legislator indicated support for the Council's issues.

Terry McFillen reported that the meetings with Senator Mills and Representative Landry were informative and commended Council staff on their preparation.

Donna Breaux reported on meetings with Senator John Alario, Representative Scott Simon, and Senator Jack Donahue.

BUREAU OF HEALTH SERVICES FINANCING (BHSF) – Lou Ann Owen

Ms. Owen shared that the Children's Choice Waiver amendment will be effective February 1st for self-direction. Acumen, the fiscal agent for self-direction, has partnered with Hire My Care, and established a registry for all direct service workers. Medicaid is working toward transitioning long-term care supports and services to managed care with enrollment and benefits being the most recent issues discussed.

The implementation date for dental services is scheduled for May 1st. The services provided will be all medically necessary dental services for children ages 0 to 21 and denture services for persons age 21 and over.

Thirteen Applied Behavior Analysts are enrolled with Medicaid and four children are currently receiving services. Medicaid is issuing an emergency rule that ABA services will be provided under the state plan effective February 1st.

Medicaid intends to have the 1915C Waiver for children with severe emotional disturbance in all areas of the state by July 1st.

Medicaid just became aware of some issues with the Behavioral Health Partnership that involve persons with developmental disabilities. The department is working very hard with Magellan to resolve some of those issues.

AFTER LUNCH PRESENTATION

SPECIAL EDUCATION MONITORING REPORT – Steven Osborn and Bernell Cook, Department of Education

Mr. Osborn and Mr. Cook provided an overview of the Special Education Monitoring process used by the Department of Education.

DEPARTMENT OF EDUCATION – Steven Osborn

Mr. Osborn reported on proposals to change promotion policies that will relax the retention policies for students in fourth and eighth grades who do not pass the LEAP/PARCC tests for the next two years.

Mr. Osborn asked the Council for feedback to help design and develop a diploma system that makes sure that every child who graduates is able to leave with something that helps students be employed and shows the students have skills.

ADVOCACY CENTER (AC) – Stephanie Patrick

The state is working to change the rule that people cannot get long-term care and hospice services together.

Ms. Patrick encouraged the Council to reach out to people in advance of the fall election to make sure everybody knows about their voting rights.

Ms. Patrick shared the Advocacy Center's 2014 legislative agenda as follows:

- Funding for the Ombudsman project (currently funded by the Council) to expand from the New Orleans region to the Baton Rouge region.
- Additional protection of discrimination against people with disabilities regarding housing and employment.
- Medicaid Expansion.
- Medication administration changes for people on self-direction and people who are not on self-direction.

The Advocacy Center is also working on restoration of cuts to home nursing hours for children under three.

The Advocacy Center is concerned about implementation issues with the Coordinated System of Care, a special program for children with mental health issues at risk of institutionalization. The Advocacy Center will seek public comment for their planning next year and Ms. Patrick will email the Council an online survey.

OFFICE OF AGING AND ADULT SERVICES (OAAS) – Kristen Kliebert for Hugh Eley

Ms. Kliebert indicated that the federal increase in Social Security is causing some people to lose Long-Term Personal Care Service. OAAS was able to extend service for 15 individuals.

GOVERNOR’S OFFICE OF DISABILITY AFFAIRS (GODA) – Ellis Roussel

GODA is hosting Americans with Disabilities Act (ADA) training for state workers.

OFFICE OF PUBLIC HEALTH (OPH) – Sue Berry

Dr. Berry indicated hope for a federal bill that passed the House restoring 87 percent of the cuts from sequestration to Children’s Special Health Services (CSHS).

National performance measures are being redone for the Federal Block Grant with CSHS input. Dr. Berry shared the current performance measures with the Council.

The System Integration Grant, the funding stream for many initiatives since clinics were closed, ends in June.

LOUISIANA REHABILITATION SERVICES (LRS) – Mark Martin

Mr. Martin reported that the number of individuals with closed cases or successfully rehabilitated as of December 31st was 675, which is a substantial increase from the number at the same time last year (438).

As of January 6th, 688 people are on the waiting list, down from 1,360. LRS moved 673 individuals from the waiting list in order of selection two into eligibility status.

Last year, Senator Harkin co-authored SB1356 which does away with the Rehabilitation Services Administration and moves vocational rehabilitation in every state under the Department of Labor.

Mr. Martin discussed two initiatives to increase federal funding levels.

OFFICE FOR CITIZENS WITH DEVELOPMENTAL DISABILITIES (OCDD) – Mark Thomas

Mr. Thomas shared information regarding the Centers for Medicare and Medicaid Services' (CMS) release of a final rule defining and describing requirements for home and community based settings appropriate for the provision of home and community based services.

OCDD plans to offer training for support coordination staff on self-direction and new therapies added to the Children's Choice Waiver.

Mr. Thomas shared information on the OCDD Systems Transformation Committee and the DHH Managed Long-Term Supports and Services Advisory Committee, both of which have Council representation.

HUMAN DEVELOPMENT CENTER (HDC) – Phil Wilson

Dr. Wilson encouraged Council members to consider participating in the Inclusion Matters Conference in June.

HDC received the Deaf-Blind Grant from the Office of Special Education Programs. This grant is responsible for the registry of individuals, children birth to 22, who have deaf-blindness.

HDC submitted a grant to National Institute for Health for transition of youth with Autism Spectrum Disorders and is applying for a Post-secondary Education Grant to determine how to better align policies and practices with the goals of LRS.

The Louisiana Autism Spectrum and Related Disabilities Project (LASARD) Project has been funded again for one year.

UNFINISHED BUSINESS

None to be discussed.

NEW BUSINESS

None to be discussed.

PUBLIC COMMENT

None.

ANNOUNCEMENTS

The next Council meeting is April 16th and 17th.

ADJOURNMENT OF BUSINESS MEETING

MOTION PASSED. Motion to adjourn made by Mark Martin, seconded by Rocky Fuselier, passed without objection.