

Executive Director's Report April 18-19, 2012 Council Meeting

Budget

- The budget report with expenditures through February 2012 is included in the packet.

Membership Update

- The Governor reappointed Sam Beech, Brenda Cosse', Kay Marcel, Mark Martin, and Nanette Olivier and appointed Stephanie Patrick to the Council.
- We are still awaiting the reappointment of Phil Wilson and the appointments of Deshae Lott Sadow, Erin Smith, Patsy White and Kris Hebert.
- Recruitment will begin shortly for applicants for Council members whose terms will expire at the end of this year.

Staff Update

- Brandi Jones was hired on February 27th as our new Program Monitor with major responsibilities over LaCAN and the Families Helping Families contracts.

DD Council Federal Appropriations

- We received notification on February 14th that DD Councils were level funded at \$75 Million in the President's Fiscal Year 2013 budget. This was regarded as a victory by the National Association of Councils on Developmental Disabilities (NACDD) in this fiscal climate.

Family Forums on Individual and Family Supports

- In collaboration with the Office for Citizens with Developmental Disabilities (OCDD), the Council co-hosted the remaining four forums in Regions I and X this past quarter, bringing the total to twenty across the state. Individuals with developmental disabilities and their families shared their experiences with the Act 378 Individual and Family Support Program.
- OCDD is working on a compilation of the comments made at the forums for the Act 378 Committee and OCDD's Executive Staff so recommendations for improvements to the program can be made.

Advocacy Activities

- We worked very closely with the Department of Health and Hospitals (DHH) to develop a proposal for the Money Follows the Person (MFP) initiative that we felt could pass the legislature. SB227 was filed by Sen. Fred Mills to give DHH the flexibility to implement the MFP initiative. However, DHH discovered MFP could be implemented without the legislation therefore a decision was made by Council leadership not to go forward with the bill. As a result of the Council first bringing this proposal to the DHH Secretary and our ongoing advocacy, DHH is very committed to this initiative and plans to move forward to fully implement it.
- As verbally reported at the January Council meeting, negotiations with DHH on means testing for families of children receiving/applying for the Flexible Family

Fund (formerly Cash Subsidy) continued at our quarterly meeting with Secretary Greenstein in January. As a result of our discussion, he agreed to delay any policy changes to allow us to try and reach a compromise. This topic will be on the agenda for our next quarterly meeting scheduled for April 16th.

- As directed at the January Council meeting, a letter was sent to Julia Kenny opposing the draft policy restricting family members serving as Direct Support Professionals. (attached)
- Comments were submitted to OCDD regarding proposed policy changes to EarlySteps, the state's early intervention system. The comments included opposition to changes that would limit access through stricter eligibility criteria and implementation of family cost participation. The letter also addressed the complaint process and provider rate cuts, which are not being proposed at this time, but could be considered in the future if program expenditures continue to exceed revenue.
- At the March Board of Elementary and Secondary Education meeting we spoke in favor of an item correcting a typographical error in the January Register Notice of Intent to modify Bulletin 1706 – Regulations for Implementation of the Children with Exceptionalities Act – Regulations for Students with Disabilities (LAC 28:XLIII.540, 541, 542, and 543). The error failed to include the requirement for schools to notify parents within twenty-four hours of when their child is restrained or secluded.
- As a result of Council and LaTEACH recommendations, the Special Education Advisory Panel adopted a position that any school accepting public funds should accept and provide appropriate services to all students.
- Several legislators have been visited to provide information and support to some of our Council members and LaCAN/LaTEACH members. Council staff also participated in ten roundtables to support our LaCAN Leaders and LaTEACH Coordinators and assist in educating legislators on the Council's agenda throughout the state.
- Fact sheets were developed and revised as needed on the Council's advocacy agenda issues. Letters were written and delivered to legislators on several issues according to the Council's positions.
- LaTEACH members have been supported in testifying before three legislative committees in regard to ensuring students with disabilities are provided equal access in the proposed educational reforms.
- LaCAN hosted a "yellow shirt day" in the Appropriations Committee in support of funding for an additional 200 NOW slots when DHH's budget was being heard. Committee members took notice and acknowledged the need for additional slots. The Region IX Leader was interviewed on the evening news.

Administration on Developmental Disabilities (ADD) Self Advocacy Summit

- Rocky Fuselier will represent the Council in Chicago on April 19-20 at ADD's Self Advocacy Summit. Other organizations making up Louisiana's team include People First (two representatives), the Human Development Center, the Advocacy Center, OCDD, and the National Youth Leadership Network. Two "at large" self advocates will also be attending.

- The purpose of the regional summits being held across the country is:
 - to assess what is currently happening in the states in self-advocacy – the support structures, activities, accomplishments and challenges;
 - to plan steps ADD can take to strengthen and enhance current efforts at the state level;
 - to develop recommendations for actions ADD can take at the national level;
 - to develop policy recommendations that can lead to a stronger, more effective, and long lasting self-advocacy movement across the country.

NACDD Technical Assistance

- Our grant application for technical assistance from NACDD was approved for \$2150. This will cover the cost of the La. Association of Nonprofit Organizations' consultant to assess our Council meeting structure and recommend improvements.

Collaborative Efforts

OCDD Mortality Review Committee

- Of the twenty-five cases reviewed, the Committee found no abuse/neglect issues and three systemic concerns were noted.
- Corrective action plans were requested of the applicable providers regarding direct support documentation, the provision and documentation of training in medical issues and implementing a process for addressing circumstances under which a parent does not cooperate with treatment (education/training, reporting neglect, etc.).

La. Rehabilitation Council (LRC)

- The LRC plans to educate the legislature on La. Rehabilitation Services and the funding drawdown issue and advocate for an increase in state appropriations.
- The LRC reduced its meetings from six to four per year.

BrightStart Early Childhood Advisory Council and Professional Development Committee

- BrightStart brings areas around early childhood development together. For example, BrightStart has brought together the offices of Infant Mortality Review and Department of Children and Family Services to collaborate on infant mortality.
- The Advisory Council discussed the importance of a quality rating system to help parents choose high quality child care to enhance their child's social and emotional development.
- The Professional Development Committee discussed creating a professional development system that trains and prepares early childhood educators. Pathways certified trainers will provide four days of training in Shreveport, Lafayette, New Orleans, and Baton Rouge in March, April, May and June, respectively.

Money Follows the Person Grant Coordinating Committee

- This committee is meeting again after a hiatus of twelve months. The Council will be represented on a core group that will be called together to provide input on project decisions that must be made within short timelines.

Meetings Attended Since January 1, 2012

Meeting w/ J. Kenny, M. Thomas, A. Bamburg re: Money Follows the Person (MFP) – January 3

Family Members as Paid Caregivers Work Group – January 5

ADD Self Advocacy Summit Meeting – January 10

State Interagency Coordinating Council (SICC) – January 11

LaCAN Leaders Conference Call re: MFP – January 13

Quarterly meeting with Sec. Greenstein, K. Kliebert, J. Kenny, S. Beech, K. Marcel – January 17

Council Meeting and Orientation – January 17, 18, 19

Region IX Legislative Roundtable in Mandeville – January 24

Region X Family Forums on Individual and Family Support – January 25

Partners in Policymaking – January 27

Region I Family Forums on Individual and Family Support – January 31

Meeting with Sen. Fred Mills, K. Marcel, B. Polotzola, and DHH staff re: MFP – February 2

Region II Legislative Roundtable in Baton Rouge – February 2

National Assn. of Councils on Developmental Disabilities (NACDD) Finance Committee Conference Call – February 9

Meeting with Providers and DHH re: MFP – February 10

Region V Legislative Roundtable in Lake Charles – February 15

Meeting with Mark Thomas and Amy Bamburg re: MFP – February 24

Meeting with Providers and DHH re: MFP – February 27

Meeting with Sen. Jack Donahue and LaCAN members – March 1

House Appropriations Committee re: DHH Budget – March 26 -27

Senate Health and Welfare Committee re: SB227(MFP) – March 28

MFP Grant Coordinating Committee – March 29



Louisiana Developmental Disabilities Council

Post Office Box 3455, Baton Rouge, Louisiana 70821-3455
1-800-450-8108 (225) 342-6804 Fax (225) 342-1970



February 9, 2012

Julia Kenny
Assistant Secretary
Office for Citizens with Developmental Disabilities
P. O. Box 3117, Bin #21
Baton Rouge, LA 70821

Dear Julia:

The La. Developmental Disabilities Council opposes any restriction of family members serving as Direct Support Professionals (DSPs) for waiver recipients.

The Council acknowledges that Act 333 of 2008 requires criteria to be established regarding family members of recipients serving as DSPs; family members to meet the established criteria; and family members to receive a waiver from DHH stating that the relative is the best available appropriate DSP for the recipient.

There are already criteria in place for all DSPs to meet. Family members serving as DSPs should not be treated any differently. The Council supports family members being treated the same as any other DSP but not being subjected to any additional requirements. **To meet the requirements of Act 333, criteria can be established that specifies family members must meet all the qualification and training requirements established in rule for a DSP.**

Family members fill an often vital role in the support of the recipient and are the most appropriate DSPs in many, but not all, circumstances. This should be a team decision that is approved when the plan of care is approved. **To meet the requirements of Act 333, the Secretary can delegate authority to approve a waiver to the entity that approves the plan of care.**

The Council recognizes the department must adhere to the requirements of Act 333, however, the proposed draft policy goes far beyond what is necessary. Viewing family members serving as DSPs as an "exception" is contrary to OCDD's person-centered philosophy. A family member is often the most trusted, qualified and stable candidate for the job. In addition, capping the number of hours per week at 40 for all family member DSPs combined is far reaching and punitive.

Many self-advocates and families report that having family members as DSPs result in a higher quality of care. There is also an increase in dependability, flexibility,

convenience, privacy and confidentiality and a decrease in the likelihood of abuse. Providers also report less turnover with family member DSPs.

OCDD has reported situations where family member DSPs are inappropriately providing supports to waiver recipients and/or taking advantage of their family member and the waiver system. The Council does not doubt that this occurs in certain circumstances; however, **there are rules and regulations in place to address this abuse.** If there is real concern among the planning team that it is not in the best interest of the recipient for the family member to serve as the DSP, the CPOC should not be approved until a resolution is reached. In addition, if a family member DSP is not complying with training or documentation requirements, they should be terminated, just as any other DSP. Additional rules and regulations are not necessary and would add another layer of bureaucracy to the system and penalize those family members and recipients who do follow the rules.

It has also been reported that a large percentage of individuals requesting review by GPSORC have family member DSPs. Again, **there are rules and regulations in place to address this issue.** If an individual's plan contains IFS hours above their Resource Allocation level of need without justification, the plan should not be approved. **Creating policy that adds a layer of bureaucracy and penalizes everyone when this issue can be addressed individually is not necessary.**

Creating a restrictive policy and imposing a cap on hours is also contrary to principles contained in Louisiana's Law on the developmental disabilities service system.

*(RS 28:451.1) It is the purpose of this Chapter to provide for a **developmental disabilities services system** that values all persons with developmental disabilities and affirms and protects their fundamental rights and privileges as citizens of Louisiana ... does not diminish the right of persons with developmental disabilities **to exert control and choice over their own lives,***

*To establish a developmental disabilities system that **affirms and supports the principles of self-determination** and full inclusion of all persons with developmental disabilities to live, work, and participate in leisure activities in their community as they choose and to the extent possible.*

RS 28:452.1

*To receive developmental disabilities services and supports **consistent with personal needs and choices***

RS 28:452.2

Charges the Office for Citizens with Developmental Disabilities with providing developmental disabilities services and supports consistent with the following principles, to the extent possible:

*A. Supports assist in enabling people to **exercise self-determination in their lives.***

In a report on family caregivers published by the National Association of State Directors of Developmental Disabilities Services (NASDDDS), Caring Families...Families Giving Care: Using Medicaid to Pay Relatives Providing Support to Family Members with Disabilities, the need for paying family members as caregivers is evidenced by 46 of the 48 responding states indicating they allow this practice, largely to address the shortage in the DSP workforce. States also acknowledged in the report that family members provide quality and trusted care that is preferred to many recipients and have found it to be a cost-effective practice. Eleven states have more lenient policies than Louisiana, allowing legally responsible relatives to provide paid supports.

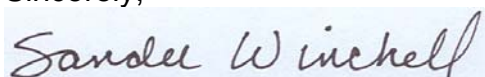
NASDDDS concludes in their report that states overwhelmingly support the use of family members as paid caregivers, noting benefits to individuals, families and the overall service system.

From our own research, we found that of states that cap the number of hours family member DSPs can work to 40, we could find only one (MN) that used a combined cap for all family members. Conversely, we found many states (ME, NY, VT, WS, TX, IL, VA, MT, UT) that have no restriction on the number of hours a family member DSP can work.

The NASDDDS report acknowledges there are concerns that are worth addressing to assure the practice of using family member DSPs is in the best interest of the individuals served. The Council agrees; however, believes Louisiana already has those safeguards in place that simply need to be enforced. Resource allocation, person centered planning and team decision making can assure that an individual receives quality services from people who are qualified, trusted, and have the best intentions.

The Council looks forward to working with you to meet the minimum requirements of Act 333. We believe this can be done while maintaining a person's right to "exert control and choice over their lives" which should include choosing a family member to serve as their DSP. This option should be easily available to them and not require bureaucratic red tape to access.

Sincerely,



Sandee Winchell
Executive Director

c: Mark Thomas