Impossible to Justify

Louisiana spends $191 million per year for 1,112 people with developmental disabilities to live away from their communities in six developmental centers.* Individuals with disabilities, family members and advocates across the state are calling for an action plan for the expeditious consolidation and closure of the state’s developmental centers. It has been proven that people with the most severe disabilities can and do live successfully in their own homes in the community with waiver supports and have a better quality of life. Their supports cost less than those in institutional settings. Metropolitan Developmental Center (MDC) in Belle Chasse was closed successfully. Others should be closed as well.

The recent discovery of multiple and long-term cases of abuse of residents at Pinecrest Developmental Center highlights the issues inherent in the current institutional system that segregates and isolates individuals with developmental disabilities from society. Several employees were arrested and charged with numerous crimes related to the abuse, but it is particularly disturbing that Louisiana is willing to expend an average of $171,000 annually per person to have these citizens subjected to this abuse. These individuals with disabilities could live in their communities and have neighbors, friends, and relatives provide better oversight of their supports and care than is available in these costly, segregated institutions.

Per capita, Louisiana serves more than twice as many people in developmental centers as the national average and ranks fourth in the nation in the number of residents in developmental centers. Nine states and the District of Columbia have closed all of their developmental centers. Sixteen other states have reduced their number of developmental centers by 50% or more. Five of these have only one remaining open. (Continued on page 10)

A Home with My Sister

Minnie Hendrix works an eight hour day in the laundry department at Hilltop Nursing Home, and her sister Viola works part-time doing general cleaning at the local Burger King. Both of them enjoy going to church, going out to eat, visiting friends, and shopping. These ladies, in their fifties, share a house in Alexandria and share the household chores. They are active in their community and enjoy their jobs – and their lives.

That hasn’t always been the case. For much of their adult lives, they were residents of Pinecrest Developmental Center. In 1996, after being on the waiver waiting list for five years, they both received a waiver slot and moved into their own home. They receive minimal supports at home from a supported living provider and they perform their jobs independently at work. Minnie and Viola are just two of many living examples who demonstrate that individuals with disabilities of all levels of severity can and do live successfully in the community after being institutionalized for many years. With proper supports, individuals with disabilities can live in their own homes, rather than having to be segregated from their communities. Just ask Minnie and Viola Hendrix.
November 4th Election –
A Milestone For People with Disabilities

On November 4, 2008, approximately 67% of all eligible Louisiana voters (1,980,377 people) voted. In this election, a record number of voters took advantage of early voting, many had the opportunity to vote via the audio ballot, and many called the Advocacy Center’s voter hotline for help. However, this election also revealed the need for significant improvements to increase accessibility for voters with disabilities.

November 4th marked the first presidential election when voters could vote early in person without an excuse and the lines outside many early voting locations showed that many voters took advantage of this opportunity. Also, voters with disabilities and seniors benefited from changes in the Election Code that allow them to vote absentee by mail more easily and to receive ballots for each election automatically.

This election also marked the first time that voters with disabilities were able to vote for presidential candidates via audio ballot. All precincts and early voting locations are equipped with audio ballot attachments, which are available to voters by request. The Advocacy Center continues to monitor voters’ access to audio ballots and encourages voters to take advantage of this opportunity to vote privately and independently.

The Advocacy Center’s voter hotline was a great success. Staff received approximately 330 calls for assistance, both prior to the election and on Election Day. Most callers requested information about where to vote, transportation resources, and laws pertaining to voting issues for people with disabilities.

Additionally, Advocacy Center staff surveyed 115 polling places throughout the state to assess accessibility. Overall, this was the biggest disappointment. Many surveys indicated barriers to accessibility, despite efforts to educate poll workers and election officials. Staff members were able to fix some of the problems on Election Day and will continue advocating for permanent improvements.

The TriAngle encourages individuals who were impacted by barriers at polling places or faced other problems to complain. Individual complaints are one of the most effective advocacy tools. The deadline to file a complaint with the Secretary of State’s office about voting problems is ninety (90) days from the final certification of the federal election in question. For help filing a complaint regarding disability issues, call the Advocacy Center at 1-800-960-7705 or 1-866-935-7348 (TTY) or email: advocacycenter@advocacyla.org. For information on filing a complaint about other issues, visit www.geauxvote.com.

The 2009 election schedule is sparse. Regularly scheduled elections will be held on March 7, April 4, May 2, October 17, and November 14, 2009. Check with election officials in your parish or with the Advocacy Center to find out more about these elections. Don’t forget, the Advocacy Center will staff its election hotline for all elections – 1-800-960-7705.
Council’s Legislative Agenda Set

Three public policy issues top the Council’s legislative agenda for the 2009 Legislative Session:

• Develop a plan for the expeditious consolidation and closure of the state’s developmental centers;
• Implement the resource allocation model across all settings (waiver and residential services); and
• Maintain the original intent of the New Opportunities Waiver (NOW) Trust Fund (to solely fund new slots)

Accomplishment of these objectives will result in a more cost efficient developmental disabilities system able to serve more people with developmental disabilities, reduce the waiver waiting list, and begin to transform Louisiana from a state that has one of the highest rates of institutionalization in the nation to one that welcomes its citizens with disabilities into its communities. The Council and LaCAN will also be advocating for the appropriation of existing NOW Trust Fund dollars for 2,000 new waiver slots in the 2009 session.

Inclusive Schools Art Contest

The Council’s 2008 Art Contest was a great success, with almost 100 poster, artwork and essay entries culminating in an awards ceremony on December 4th at the Cook Conference Center at LSU. The winning art was also displayed at the Nicholls State University Disability Awareness Day in October, the DD Council Office in November, the Board of Elementary and Secondary Education (BESE) meetings in December, and the Governor’s Outstanding Leadership in Disabilities Awards (GOLD) ceremony, also in December. At the BESE meeting, Superintendent Paul Pastorek recognized the art contest and also thanked the participating schools for their work in promoting disability awareness and inclusive education. For a list of winners including their teachers and schools, visit www.laddc.org under Council Initiatives.

2009 LIEA Indian Youth Camp

LA Indian Education Association is seeking 7th – 12th grade American Indian students with disabilities for its 10th Anniversary Indian Youth Leadership Experience, March 13 – 15th in Bunkie, LA. Stipends for the registration fee may be available for those who qualify. Contact Robbie Gray at 800-450-8108 or rgray@dhh.la.gov.

Partners Reunite to Reignite

Forty Partners in Policymaking graduates from the past 11 years gathered in Baton Rouge on November 14 – 15th to reenergize and rekindle the advocacy fire in their hearts. They were provided a wealth of information from keynote national speaker Allan Bergman and several Louisiana experts. The graduates left with plans to continue to network with one another and reach out to graduates in their regions unable to attend the reunion as they work together on issues relevant to their communities and advocate for statewide systems change.

Disabilities Information Access Line (DIAL) Changes

The Council discontinued its DIAL program and has allowed the LA Association of Families Helping Families (LAFHF) to adopt the DIAL number. Beginning January 1st, DIAL calls are being received by a service operated by LAFHF and calls are being routed to the appropriate FHF regional center. The Council wants to thank Robert Caulk for 18 years of dedicated and professional service in handling DIAL calls. Robert will continue to provide families with information and support in his new role with LA-CHIP (Children’s Health Insurance Program).

DD Council Seeking Applicants

The Council welcomes applications for membership year round but recruits applicants annually from areas where expected vacancies are anticipated in the next year. Individuals with developmental disabilities and immediate relatives of people with developmental disabilities are encouraged to submit an application for Council membership from the Acadiana and Northeast regions of the state.
HDC Welcomes New Staff

Ms. Alycia Burch joined the HDC staff in November 2008. She and her 13 year old daughter, Victoria, live in Pineville. Alycia works as an Employment Advisor on the Supported Employment Continuous Improvement Project (SECIP), serving the northern area of the state. Ms. Burch earned her BA in business, with an emphasis on healthcare management. She is currently working on completing her master’s degree in education. She has over 12 years of experience working with individuals with developmental disabilities.

Sheree Tarver is currently a Research Associate for the Data Accountability Center (DAC), an OSEP-funded project conducted by Westat and HDC. In May 2008, Ms. Tarver graduated from Loyola University New Orleans with a Bachelor’s degree in psychology and a minor in mass communications. In 2008, Sheree received the Magis award from Loyola University for her leadership and maturation during the four years she was there. Sheree was involved in multiple student organizations including positions on the Student Government Court of Review, New Student Orientation, and the Black Student Union. In her free time Sheree loves to dance, which has been her lifelong hobby. She was also the choreographer for a dance group she co-created for students at Loyola, called Southern Made. Her current research interests include disproportionality in public schools and research-based methods of intervention.

In the fall of 2008, Ms. Cheryl Every joined HDC as a Research Associate for the Louisiana School Psychology Internship Consortium (LAS*PIC). Her primary responsibilities include managing data collection systems and producing technical reports for LAS*PIC. Ms. Every served as an administrative assistant for thirteen years with the New Orleans Public School System. She recently received her B.S. in Business Administration from the University of Phoenix and is both a proud mother and grandmother.

Dr. Nicole Lasserre-Trosclair (aka “Nikki”) joined the HDC staff in Fall 2008 and serves as co-coordinator of a newly-established pilot project designed to provide intensive services to young children with (or at risk of being diagnosed with) autism spectrum disorders. This pilot project is designed to strengthen the skills and enhance training and support provided by childcare providers, EarlySteps professionals, and family members.

Nikki lives in Destrehan with her husband Guy, and infant son, Reed. She earned her undergraduate degree and Ph.D. in School Psychology at Louisiana State University (Baton Rouge). Subsequently, Nikki completed HDC’s School Psychology internship program (LAS*PIC), working in Lafourche Parish as a School Psychology Intern and Discrete Planned Interventionist. She was responsible for developing and maintaining behavior plans for individuals diagnosed with emotional disturbance and for developing behavioral interventions and academic programs for children with autism.
Mirvis Receives Award

Diane Mirvis received the Meritorious Award at an Awards Ceremony honoring people who have contributed to the vocational rehabilitation of persons with disabilities in Region VI (Texas; Louisiana; Arkansas; Oklahoma; and New Mexico). Diane was acknowledged for her long-term advocacy on behalf of people with disabilities and her willingness to work with rehabilitation professionals toward the goals of their mutual clients. Susan Bushnell and Lois Simpson were there to cheer Diane on, as was AC Board member, David LeGendre, and many other friends, colleagues and relatives of Diane. Congratulations, Diane, for an award well deserved.

BIALA Update

The Brain Injury Alliance of Louisiana (BIALA) is a non-profit organization that works to improve the quality of life of persons with brain injury and their families. BIALA has grown significantly in 2008 and anticipates even bigger accomplishments in 2009. BIALA recently hired Madonna Franco, a survivor and advocate of brain injury, as a part-time Resource Coordinator. Her office is located in the offices of Advocacy Center, where she responds to questions and requests from the brain injury hotline and assists the Board of Directors in conducting business to further expand the organization. BIALA has recently applied for funding from state resources, and is planning its March 2009 conference and fundraising events in the summer. BIALA is looking for new board members with an interest and experience in brain injury and welcomes new members to the organization. For more information, call 1-800-500-2026 or visit www.biala.org.

Advocacy Center Launches Annual Campaign

Letters have recently gone out to friends and supporters of the Advocacy Center, asking for an annual contribution to support the work of AC. Advocacy Center is seeking funds to support its legislative advocacy and training activities. All contributions are tax deductible and can be made via check or by accessing our website www.advocacyla.org and paying via PayPal.

AC Welcomes New Staff

A number of staff people have joined or returned to the Advocacy Center over the past few months. Pamela Hemen and Shirley Methvin return as Case Managers on the Northshore. Marla Reissland returns as a Case Manager Supervisor, and Mark Perron returns as a Staff Attorney in New Orleans. Beth DeBlanc was recently hired as a Client Advocate in Lafayette. Debbie Meyer is a new Case Manager in Houma, and Jordan Chernikoff is a new Case Manager in New Orleans. Susan Godber is a new Long Term Care Ombudsman in Baton Rouge. Welcome to everyone!

Gustav/Ike Case Management Program

Advocacy Center received funding from Catholic Charities USA to provide disaster case management services to individuals affected by Hurricanes Gustav/Ike. Services will be provided in the following Parishes: Orleans, Jefferson, Plaquemine, Terrebonne, St. Tammany, and Tangipahoa. Individuals affected by Hurricanes Gustav and Ike can call 1-877-893-0283 to request case management services.

Louisiana’s Work Incentives Planning & Assistance (LAWIPA) Coalition

In 2009, Advocacy Center will receive funding from Louisiana’s Medicaid Infrastructure Grant (MIG) to hire an additional full-time Community Work Incentives Coordinator (CWIC) to increase services in rural parishes of S.E. Louisiana. WIPA staff can help beneficiaries of Social Security with advice on how work incentives can help them secure, maintain, or advance in employment. To request WIPA services, call 1-800-942-8104.
A Tribute to Mary Anne Perault: To Know Her Was To Love Her

The disability community lost an amazing advocate and friend on October 19, 2008, when Mary Anne Perault passed away after only 46 short years. Although her life ended far too early, the memory of Mary Anne and her advocacy efforts will last a lifetime.

Mary began her career in the disability field with Resources for Independent Living, where she helped people move out of nursing homes. She later worked for the Governor’s Office of Disability Affairs, as a disability specialist and a benefits specialist. She advocated for the independence of people with disabilities through employment and advised those who received disability benefits how working would affect their benefits. During Governor Mike Foster’s administration, Mary was appointed as the Executive Director of Disability Affairs and continued for a time as director under Governor Kathleen Blanco’s administration. Most recently she worked for The Arc of Louisiana, advocating for accessible, affordable housing for people with disabilities.

Many people did not recognize Mary as having a disability, because she never allowed any limitation to slow her down or silence her up when her voice needed to be heard. Mary advocated for and believed that all people with disabilities had a voice worth hearing. She practiced this belief, as she advocated for people with disabilities who wanted to live in the community rather than an institution, who wanted a real job with real pay, and who needed to understand their benefits so they could be successful.

Mary’s love of life was infectious and was apparent in the wonderful stories she told. Although she is no longer here in body, her spirit lives on in her family and friends who loved her dearly. Her spirit also lives on in what she accomplished for people with disabilities, as a result of her advocacy efforts. Mary will never be forgotten.

Agency Spotlight - Louisiana Association of Families Helping Families

Families Helping Families Resource Centers are family-directed resource centers that offer an array of supports to individuals with disabilities and families in each region of the state. Core services and supports include, but are not limited to, information and referral; education and training; and peer-to-peer support.

Eight of the Families Helping Families Resource Centers around the state have joined together in the formation of the Louisiana Association of Families Helping Families (LAFHF). The purpose of this professional association is to provide a mechanism for its members to share management expertise, strategies, and resources that enhance the ability of its regional family resource centers to serve constituents in an efficient and cost-effective manner, as well as to provide a protocol for both fiscal and programmatic accountability for each FHF center with an established membership criteria.

The LAFHF took over the DD Council’s DIAL number, (800) 922-3425, on January 1st and can also be reached at laafhf@yahoo.com. Members of the association regularly check this email address for issues concerning the association.
National Principles for Financing Long-Term Services and Supports

An estimated ten million Americans currently have needs for long-term services. The number of individuals needing long-term services in the United States is projected to increase to 26 million by 2050. However, the nation lacks a coordinated, national public-private system for delivering long-term services and supports. Nearly half of all funding for these services is now provided through Medicaid, which is a growing burden on states and requires individuals to become and remain poor to receive the help they need. There is also an institutional bias in Medicaid, whereby, nationally, approximately two-thirds of all spending is directed towards nursing homes and other institutions, instead of preferred community-based services and supports. This institutional bias is even more pronounced in Louisiana.

The Leadership Council of Aging Organizations (LCAO) and the Consortium for Citizens with Disabilities (CCD) together represent over 150 organizations representing seniors, people with disabilities, and providers of health, housing, and supportive services. Recently, the leadership of these important consortia agreed on a set of joint principles for reform and for financing long-term services and supports. The principles adopted by the two coalitions call for a national solution. The plan should give consumers access to a broad array of support options, including comprehensive home and community-based supportive services. The new public financing system should be as universal as possible, with a limited choice to opt out. This new system will relieve pressure on Medicaid. The new system should promote independence and dignity across the lifespan by ensuring beneficiaries the right to control and choose what services they receive, how and where they are delivered, and who provides them.

Advocates for seniors and individuals with disabilities across the country have banned together to urge members of Congress to introduce legislation that is consistent with these principles. The Community Living Assistance Services and Supports Act, (CLASS Act), which is supported by President-Elect Barack Obama, is compatible with the LCAO-CCD principles. The CCD and LCAO principles provide the Obama Administration and Congress with a blueprint for inclusion of long-term care, within the broader health care reform discussion. The principles are:

- **National Problem, National Solution** – Recognize that, although states, communities, families, and individuals have important roles to play, financing for long-term services and supports is a national problem that requires a national solution.
- **Universality with Limited Opt-Out** – Create a public program that allows all people, including those with disabilities and/or near retirement, the opportunity to contribute to and prepare for the costs of long-term services and supports. Make participation as convenient as possible, but give people the limited choice to opt out.
- **Public/Private Partnership** – Provide a strong foundation of protection, while providing opportunities for personal planning that include a role for private sector options.
- **Affordability and Risk Pooling** – Provide for broad pooling of risk and appropriate low-income subsidies to make premiums affordable for all people, regardless of income and health status. Ensure that a new program does not force people to impoverish themselves to qualify.
- **Fiscal Responsibility** – Provide actuarially sound funding, such as through voluntary premiums that build reserves over time sufficient to pay for future needs in a way that is affordable to individuals and to society as a whole.
- **Relieve Pressure on Medicaid** – Provide long-term services and supports funding mechanisms to help take the pressure off of future Medicaid expenditures, while preserving the guaranteed safety net.
- **Consumer Choice and Control** – Promote independence and dignity across the broad continuum of services and supports by ensuring beneficiaries the right to control and choose what services they receive, how and where they are delivered, and who provides them.
- **Support Family Caregivers** – Recognize and support the central role families and other informal caregivers play in planning for and providing long-term services and supports, including developing strategies to support working caregivers to maintain their financial security.
- **Invest in Quality Care and Quality of Life** – Target additional funding to ensure sufficient training and compensation for the workforce and to strengthen oversight, enforcement, and advocacy programs that improve quality of life and quality of care in all settings.
Did You Know?

LAFairHousing.org - Did you know there’s a website devoted exclusively to housing issues for people with disabilities in Louisiana? It’s www.lafairhousing.org. Go there and you will find the “Housing Fact of the Month” a calendar of upcoming housing-related events, housing-related legislation of interest, and a list of publications you can download. Since Hurricanes Katrina, Rita and Gustav devastated south Louisiana, accessible, affordable housing has been of prime interest to people with disabilities in Louisiana. To ensure that you know your rights related to housing, don’t forget to visit lafairhousing.org.

LAHousingSearch.org is a free service to list and locate affordable, special-needs housing in Louisiana, both rental and for sale. This service, which is updated daily, is available online or through its call center: 1-877-428-8844 (toll free); 7-1-1 (TTD/TTY); or via relay service. LAHousingSearch.org

Unityhousinglink.org is a free, online service that can assist renters with locating affordable housing that meets their needs in the Greater New Orleans area (Parishes of Orleans, Jefferson, St. Bernard, and Plaquemines). This site provides comprehensive descriptions of available properties, which have rent limits at 80% of the current area Fair Market Rent. For assistance in using this website, call UNITY Welcome Home at 504-899-4589 (extensions 111 or 114); call toll free at 888-899-4589; or e-mail housinglink@unitygno.org.

Sharedhousingofneworleans.org is a free service in Orleans and Jefferson Parishes that matches homeowners (individuals with disabilities or who are elderly and require assistance to remain in their homes) with home seekers. No money is exchanged in this program: homeowners provide room and board; home seekers provide light housekeeping and companionship. For more information, call 504-896-2575 or e-mail strauss@sharedhousingofneworleans.org.

A research study about Hurricane Katrina survivors who have a disability, diabetes, or another health impairment that limits daily activities is being conducted by The Center on Disability and Development at Texas A&M University. Eligible participants can receive up to $50. For more information, call 866-578-4366 (toll free), or contact Aaron Resch at jaresch@tamu.edu or 987-862-6605.

Autism Insurance Coverage - In January 2009, Act 648 goes into effect, mandating insurance coverage for children with Autism Spectrum Disorders for any health insurance and Office of Group Benefits policy that is issued to employers of more than 50 people. For more information, go to: http://www.laddc.org/main/?page_id=336

Save the Date!
The Brain Injury Alliance of Louisiana (BIALA) has scheduled its second statewide conference on Friday, March 27, 2009 from 10 a.m – 3:00 p.m. Survivors, families, friends and brain injury professionals are invited to attend. This year’s conference will be held at Ochsner Hospital, 1514 Jefferson Highway in New Orleans. For more details and registration information, call 1-800-500-2026.

Families Helping Families Resource Centers in each region of the state sponsor local and regional workshops on issues such as education, transition, advocacy, community supports, specific disabilities, and other topics of interest to people with disabilities and their families. For information on workshops in your area, contact your local Families Helping Families. Contact information on each center can be found at http://www.laddc.org/main/?page_id=283 or by calling 1-800-450-8108.
State Superintendent of Education Commits to World-Class Special Education System

Superintendent of Education, Paul Pastorek, recently declared his commitment to creating a "world-class" special education system in Louisiana. To begin the daunting task, a two-day summit was convened in Baton Rouge in Fall 2008 to discuss what is currently working, difficulties, and possible solutions. Invited participants included a group of nationally recognized consultants; members of the Louisiana Department of Education; representatives from parent groups; educators; and other stakeholders. By the close of the second day, the group had identified a few broad recommendations that were given to Superintendent Pastorek for his consideration in January 2009. The assembled group generated ideas that fell into four broad recommendations, described below.

First, before students are referred to special education, the general education system, with support from the special education infrastructure, must implement a statewide system of tiered research-based interventions for reading, math, and behavior utilizing Response to Intervention (RtI) and Positive Behavior Intervention and Supports (PBIS) models. This system needs to be implemented with fidelity, to ensure that students do not receive special education labels and services simply because they lacked appropriate instruction and supports within general education.

Second, to enable all students with disabilities to access and successfully participate in the general education curriculum, core indicators that reflect collaborative practices for general and special education teachers focusing on co-teaching, effective instructional practices, and appropriate use of accommodations and modifications to curriculum should be identified and assessed, statewide.

Third, strategies to improve special education personnel preparation, recruitment and retention are needed to ensure Louisiana’s students with disabilities are taught by highly-qualified personnel who can produce better results. Ongoing professional development and collaborative (i.e., general education/special education) planning and service delivery need to occur statewide. Models for achieving these results must accommodate the diverse abilities and needs of Louisiana educators.

Finally, attention to reconfiguring Louisiana’s special education funding formula to maximize fairness and equity was recommended. This recommendation also stipulated that the Department of Education provide ways to address local school district questions and difficulties with regard to funding.

The two-day, world-class special education summit raised awareness of specific issues (e.g., need for general education to take primary responsibility for RtI/PBIS- rather than special education) and generated consensus on other issues (e.g., the need for new models of personnel preparation with attention to specific attention to skills required for effective collaboration between general and special education). It is hoped that these recommendations will provide Superintendent Pastorek with suggestions that will support his bold leadership and assist the Department of Education to create a world-class special education system in Louisiana.
Resource Allocation Model

When the Office for Citizens with Developmental Disabilities (OCDD) implements the Resource Allocation Model with the 2,025 new recipients of the New Opportunities Waiver (NOW), funded in the 2008 Legislative Session, their average costs are expected to be $44,208 annually. The current average annual cost of an individual served through the NOW is $70,000. Beginning in July 2009, OCDD plans to phase-in implementation of the Resource Allocation Model with existing NOW recipients age 16 and up, over a three year period. This model allocates direct service hours based on an assessed level of need using an assessment tool called the Supports Intensity Scale/La. Plus. If individuals are receiving more hours than they need, a certain percentage of those hours will be phased out each year until they reach their target hours. As this new system is phased-in, a reduction in the $70,000 average can be expected.

A policy to begin implementing this model with residents of developmental centers and private ICFs/DD at the same time as waiver recipients is currently being developed by OCDD with input from stakeholders. OCDD has stated its intent to implement this model fairly across all settings.

Resident Allocation Model

When the Office for Citizens with Developmental Disabilities (OCDD) implements the Resource Allocation Model with the 2,025 new recipients of the New Opportunities Waiver (NOW), funded in the 2008 Legislative Session, their average costs are expected to be $44,208 annually. The current average annual cost of an individual served through the NOW is $70,000. Beginning in July 2009, OCDD plans to phase-in implementation of the Resource Allocation Model with existing NOW recipients age 16 and up, over a three year period. This model allocates direct service hours based on an assessed level of need using an assessment tool called the Supports Intensity Scale/La. Plus. If individuals are receiving more hours than they need, a certain percentage of those hours will be phased out each year until they reach their target hours. As this new system is phased-in, a reduction in the $70,000 average can be expected.

A policy to begin implementing this model with residents of developmental centers and private ICFs/DD at the same time as waiver recipients is currently being developed by OCDD with input from stakeholders. OCDD has stated its intent to implement this model fairly across all settings.

(Continued from page 1)

Louisiana currently has a five year plan to reduce the population in its developmental centers and to downsize two of them to less than 16, changing their status to group homes. Unfortunately, this plan is flawed. Two other developmental centers in Leesville and Columbia were downsized to group homes three years ago, now serving a combined total of 21 people, but they still occupy the same building and grounds. The total budget for these two facilities is $5.77 million. Most of that is administrative overhead, but by keeping these centers open to serve 21 people, the average cost is $274,000 per person. The individuals in these two “group homes” should move off campus, where they can be included and served in their communities for far less than $274,000/ year per person. The developmental centers in Ruston and Thibodaux, slated for downsizing to group homes should not make the same mistake. All the residents should be moved off campus into their communities, where they can enjoy a better quality of life at less cost. Savings can then be used to serve some of the thousands on the waiver waiting list.

In 2006, the legislature passed Act 555 by Senator Sharon Weston Broome and Rep. Yvonne Dorsey to capture the proceeds from the sale of immovable and movable property previously used by the Office for Citizens with Developmental Disabilities (OCDD) to expand and enhance waiver services for people with developmental disabilities on the waiver waiting list. When the last of 262 residents moved out of MDC in Belle Chasse in 2007, there were high hopes that the land would be sold, resulting in an infusion of cash into the waiver program. Unfortunately, the opposite is true. Not only has the property not been sold by the Division of Administration, OCDD is still having to pay $1.6 million/year for its upkeep! These state dollars could be used as a match to fund 120 New Opportunities Waiver (NOW) slots for new people from the waiting list. The same could be said for the properties in Leesville, Columbia, Ruston and Thibodaux. Collectively, the proceeds from the sale of the properties and the savings reaped from the extremely high cost of their operations could provide a sizable allotment of funds.

These are the obvious decisions that can be made by our policy makers, and in this time of economic gloom and uncertainty, they will hopefully be made quickly. But vacating and selling the properties in these five cities will not be enough to bring Louisiana to the national average in the number of people served in developmental centers. And it will also not be enough to take us from a developmental disabilities system of “have” and “have nots.” It is impossible to justify to those on the waiting list how the state can spend an average of $171,000 per person per year while they have to wait for up to nine years for waiver services. Louisiana’s unbalanced system will not transform until our policy makers demand an accelerated plan to consolidate and close our state’s developmental centers and use the savings to serve people on the waiting list.

There is an argument for this plan even more compelling than cost, national statistics, best practice, quality of life and fairness – it is human rights. Segregation in developmental centers deprives individuals of the benefits and freedoms afforded by participating in community life. It prevents countless reciprocal and loving relationships and robs Louisiana communities of the gifts and talents of thousands of our citizens.

* The names of the state’s developmental centers were changed in 2007 to Supports and Services Centers. Many people still refer to them as developmental centers and the TriAngle chose to use that more common name in this issue.
In October 2008, news broke about the arrest of five employees of Pinecrest Developmental Center for allegedly abusing residents. The investigation revealed that up to eight residents had been victims of abuse for up to a year and a half. The sheriff’s report indicated that employees who witnessed the abuse were threatened with their jobs if they reported the abuse. While any single incident of abuse is sickening, there are a number of issues that make this most recent finding particularly egregious. Given the length of time and severity of the abuse and the fear of other employees blowing the whistle, it is necessary to hold accountable those who are responsible for monitoring the residents’ medical conditions and managing Pinecrest, as well as our state’s leaders for continually failing to acknowledge that warehousing people with developmental disabilities in these institutions (i.e., large ICF/DD Developmental Centers or Supports and Services Centers) places the residents in a culture that promotes abuse.

It would be almost refreshing if the solution would be to identify the five employees who committed the alleged acts and deal with them. However, the time frame of the abuse indicates that these incidents of abuse began occurring only six months or so after Louisiana had ended a settlement agreement with the United States Attorney General. The settlement agreement that ended in October 2006 stemmed from federal investigations and findings dating back to the mid 1990’s by the Department of Justice. The federal complaint indicated that the State of Louisiana “failed to provide reasonable safe conditions,” specifically as it related to protecting the residents from undue or unreasonable restraint, and failure to provide adequate health care, nutritional care and therapy services. In addition, it was found that there was a failure to ensure that citizens living at the institutions were adequately evaluated for placement in the most integrated setting. Basically, it was found that Developmental Centers not only failed to provide residents with basic services, but also failed to protect them from harm and unnecessarily restricted their living arrangements to these institutional settings.

This settlement agreement had an expert monitoring Pinecrest and Hammond Developmental Centers for “conduct and practices...that deprive residents of the institutions of rights, privileges, or immunities secured or protected by the laws and Constitution of the United States.” So at the time the recent incidents of abuse had begun, it would have been expected that the Developmental Center(s) had in place the best possible services and protections of residents’ rights that these institutions can provide. Unfortunately, the culture and model of isolating and segregating individuals with developmental disabilities and staff resulted in inadequate monitoring for signs of abuse and, worse, prevented others from freely reporting it. It is not appropriate to pretend that, by segregating people with disabilities, we are ensuring that they are protected and free from harm. To the contrary, the continued patterns of findings within these institutions indicate that instead of protecting residents, the system is actually designed to make them more vulnerable to continued abuse than someone who is served appropriately in the community and connected to neighbors, friends and community members. Since Developmental Centers cannot even guarantee the safety of the residents, what is the justification for maintaining these archaic institutions?

Louisiana should follow the lead of numerous other states and close its Developmental Centers.
Obama Names Cabinet Members

The whole country is eagerly watching as President-Elect Obama makes decisions about key positions in his government. So far, most of the news has been about economic and security advisors. However, two appointments hit a little closer to home for people with disabilities and seniors - the appointment of former Senate Majority Leader Tom Daschle as Secretary of the Department of Health and Human Services and the appointment of Shaun Donovan as the Secretary of Housing and Urban Development.

Daschle was a close advisor to Obama throughout the former Illinois senator’s White House campaign. Organizations seeking to expand health coverage were quick to praise the selection. “Senator Daschle has a deep commitment to securing high-quality, affordable health care for everyone in our nation,” said Ron Pollack, Executive Director of Families USA.

Shaun Donovan is the current New York City Commissioner of Housing. As the new Secretary of HUD, Donovan will play a key role in the Obama administration’s efforts to stem the rising tide of foreclosures and rebuild the nation’s efforts to expand homeownership. In turning to Donovan to lead HUD, Obama is tapping someone with broad experience in many of the critical issues confronting the department. Prior to taking on the NYC Housing Authority, Donovan managed Prudential Mortgage Capital’s $1.5 billion affordable housing investments.

Both Mr. Daschle and Mr. Donovan must be confirmed by the Senate before they can take office.

Louisiana Faces Significant Budget Cuts

As the TriAngle goes to press, Governor Bobby Jindal and state officials are addressing significant shortfalls in the state operating budget. These shortfalls have already led to midyear cuts in agency budgets for 2008-9 and even more projected cuts for 2009-2010. According to an article in the Times Picayune, *“The latest numbers from the Revenue Estimating Conference, a four-member panel that decides how much money the state can spend, also project that next year’s budget shortfall will exceed $2 billion: about $750 million more than earlier estimates.”*

It is not clear how these cuts will affect services for people with disabilities, although the Governor has already indicated that the operating budget of the Department of Health and Hospitals, which provides services to people with developmental disabilities, mental health issues, and other disabilities, will be impacted. He also announced that there will be cuts in higher education budgets. Advocates should remain vigilant as decisions are being made by state officials and should speak out about how the cuts will impact them and their family members.

The TriAngle will provide more information in the April 2009 issue.

*Midyear cuts likely in Louisiana budget. Health care, higher education in cross hairs as revenue falls, Times Picayune, 12/16/08*
As of November 28, 2008 there were 125 open child care centers in the Greater New Orleans area, as compared to 275 pre-Katrina. It is generally agreed that the lack of affordable, high quality child care ranks next to affordable housing, in the order of challenges facing Orleans Parish families with children.

In June 2006, Agenda for Children convened a group of child-care stakeholders to develop a strategy to rebuild the child-care infrastructure in the Greater New Orleans area. Now known as the Greater New Orleans Child Care Rebuild Collaborative, the group is comprised of 12 local organizations, including Agenda for Children, United Way, the Louisiana Department of Social Services, the Human Development Center (HDC), Tulane University Department of Psychiatry, Children’s Defense Fund-Louisiana, the Institute of Mental Hygiene, Good Work Network and others. After an intensive period of needs assessment, the group decided to proceed with a fund-raising and grant-making process to help child-care centers rebuild.

The state of Louisiana also began addressing the issue of affordable, quality child care through two related initiatives. A voluntary quality rating system (QRS) for child care, called Quality Start, was implemented and the legislature produced the School Readiness Tax Credits package for child-care center owners and staff and families. The state has defined three stars as the minimum quality goal for all centers, which will qualify the center for $1,000 per year in tax credits for each child in their care who qualifies for the Child Care Assistance Program (CCAP) and children in foster care. Centers with a superior rating of 5-stars will receive $1,500 per enrolled subsidized child in their care. Both offer substantial promise of improving child care for all, and provide the assurance of increased funding if centers can attain a higher level of quality. However, preliminary indications are that the vast majority of child-care centers will have to make major improvements to qualify for the tax credits.

The Conrad Hilton Foundation awarded the Collaborative Bridge to Quality project $1.3 million in funding for a period of two years, to jump-start selected centers in achieving a higher star rating level of quality. This project will help centers “bridge the gap” by providing intensive technical assistance, coaching, and funding to improve quality, until the state tax credits are awarded. JoAnn Clarey and Dr. Gina Easterly-Taylor of the LSUHSC-Human Development Center will work with the Bridge to Quality program as project coordinator and TA coaches.

This model will help centers make sustainable improvements in the quality of child care. Based upon its success, they hope to expand the model with additional funding sources, including private philanthropy, the business community and state government. For more information, contact JoAnn Clarey at jclare@lsuhsc.edu.

Speak Out About Your Hurricane Experiences

The Advocacy Center is interested in learning from people with disabilities and the elderly how they were affected by recent hurricanes, such as Katrina, Rita, Gustav and Ike. We are interested in knowing your experiences with sheltering, evacuating, re-entering your home city, obtaining public benefits (such as FEMA and food stamps), and how the messages about the hurricanes were or were not received by you. A survey will be posted to www.advocacyla.org to help us gather input. Please complete it online or call and share your information at 1-800-960-7705, ext. 130.
In Memoriam – Ursula Arceneaux Markey  
September 13, 1946 – December 22, 2008

Ursula Markey, a much beloved leader in the social justice and disability advocacy communities in New Orleans, Louisiana, and the nation, died on December 22nd after a long struggle with diabetes. She left behind a long legacy of accomplishments that have forever changed the lives of persons with disabilities. Ursula and her husband of 38 years Dempsey (DJ) Markey began advocacy in the area of disability issues when their older son Duane began to exhibit signs of autism at an early age. Assisted by the Advocacy Center, they eventually filed suit to get Duane the specialized services he needed. That was the beginning of a lifetime of advocacy. As they learned more about disability, about inclusion, and about effective advocacy to insure the integration of people with disabilities in the community, they not only continued and refined their advocacy on behalf of their sons, but shared their knowledge with others.

Together, they founded the Pyramid Parent Community Resource Center in New Orleans, which has provided assistance to countless families seeking to improve the educational experiences of their children with disabilities. As one such parent wrote, “Ursula taught me to value my son’s positive attributes at a time when I felt helpless to help him… Ursula and the Pyramid Parent and Community Resource Center changed my life! I have to thank Ursula and DJ for their support, guidance and insight about reaching special needs children. … On behalf of so many Pyramid parents, thank you Ursula.” Similar stories and tributes poured in from around the country. From a woman in Boston: “The national disability rights movement has lost one of our most effective, inspiring leaders. I am … grateful for the privilege of knowing and working with Ursula for over 20 years.”

Throughout her life, Ursula fought for civil rights and social justice in many venues. She also was a talented painter and writer and a gifted inspirational speaker. She had a wonderful sense of humor. She shared generously of her time and talents with family, friends, and those in need.

Services were held for Ursula on Saturday December 27th in New Orleans.

Survivors include her husband Dempsey (DJ) and son Teiko Markey of New Orleans, brothers Lawrence Arceneaux of Los Angeles and Ronald Arceneaux of Kenner, and a host of family and friends. She was preceded in death by her parents, Lawrence and Velma Arceneaux, and her son Duane Markey. In lieu of flowers, the family requested donations to the Pyramid Parent Community Resource Center, 3132 Napoleon Avenue, New Orleans, LA 70125.
Steps Forward

OCDD is beginning to implement a Resource Allocation Model for new recipients in the New Opportunities Waiver that will allocate Individual and Family Support (IFS) hours according to a person’s individual level of need based on a comprehensive assessment. By fitting services to individual needs, OCDD estimates that anywhere from two (2) to twelve (12) million dollars can be saved – money that can be used to serve people who are currently not receiving services. OCDD has stated that it intends to eventually assess and apply the Resource Allocation Model to all people who are currently receiving or who apply for services, including those residing in Developmental Centers and private facilities. This positive step forward under OCDD Assistant Secretary Kathy Kliebert’s leadership should ensure that individual needs are met while freeing up dollars to serve people on the waiting list.

The Jindal Administration is rushing forward with its Louisiana Health First (LHF) Plan, in an attempt to get federal approval of the plan before the Bush administration leaves office in January. The goals articulated by LHF – better access, better quality, lower cost – are the same goals that every reform agenda aspires to accomplish. However, whether or not the LHF will achieve these goals is another matter. The key feature of the LHF is a retooling of the existing Medicaid program. The passage of LHF should not be attempted on short order. Before moving forward, there should be thoughtful debate on the part of the Louisiana Legislature and the health care and consumer community. In a Research Brief recently issued by the Public Affairs Research (PAR) Council, that group stated: “The solution is to expand coverage to achieve true health care reform. Tinkering with the management of Medicaid is likely to increase spending with little improvement in outcomes.”

Steps Backward

Why Should I Sign Up for the Online Version of the TriAngle?

- It’s better for the environment.
- Issues arrive more quickly and conveniently.
- It help editors save on publishing costs.

Make a smart choice to go paperless!

To sign up for the electronic version, visit http://www.laddc.org/pubs/triangle/ and email triangle@advocacyla.org to let us know. Please encourage friends and colleagues to sign up for the online version, too.

Thanks from the Editorial Board.
Contest winners and their teachers are pictured above at the awards ceremony held at the Cook Conference Center in Baton Rouge on December 4th. Also pictured (on the front row) are the awards ceremony keynote speakers Craig Blackburn and Lynette Fontenot, Council Chairperson.