

## Afterall, It IS All About Family!

By Rose Gilbert

In 1986 my son, Nicholas, was five years old. He was attending a non-categorical pre-school at our local school system and was about to be "classified". I'd always thought of the classifieds as "want ads", but I was soon to find out that this didn't have anything to do with being "wanted".

I attended a Project PROMPT workshop that a friend told me about. I learned about the "Education of the Handicapped Act" (now, IDEA) and the provisions within that law. I learned that Nicholas was entitled to FAPE (free and appropriate public education), a fair evaluation (not just a bunch of tests – but something that included my extensive knowledge of him), about the IEP (Individualized Education Plan – a tool by which to make his education fit his needs), and I learned that special education is a service, NOT a placement.

It would take months for me to figure out that I had embarked on a journey. A journey on which I was not prepared to travel - I had no luggage, no clothes, no money, no plan and no real desire to travel.

Twenty years later, I can only stand in awe of the opportunities I have been given to make my career in such a field. Having the privilege to experience this journey with so many dedicated, knowledgeable and caring parents and professionals is humbling.

I've traveled throughout this country and this state, learn-

ing and sharing what Nicholas has taught me. I've had the honor of participating in systems change grants, youth forums, transition planning for our community and our state. I sat on work teams, committees and councils that have affected the delivery of services through several state and local agencies – Early Childhood, Department of Education, Office for Citizens with Developmental Disabili-



ties, Medicaid, Special Health Care Services and Rehabilitative Services.

And yet, I find that the group of people that are the best teachers I've ever had, the ones that I have learned the most from – are my family - my mother, Betty, my husband, Mike, and my sons, Nick and Aaron. They have taught me the best and most unique lesson I have ever learned. I have choices.

Everyday that I have the opportunity to open my eyes, I have choices. I choose when I get up, how fast I move to get ready, what I wear, what I eat, how I'm going to treat others, where I'm going for the day, when I'll head home, what I'll fix for supper (or bet-

ter yet, whether I'll even cook), what I'll watch on tv, how long I'll read before turning out the light – the choices are endless. As I applied these thoughts to those around me – those who cannot speak or dress or feed themselves – I could only imagine what it must be like, not being able to make choices.

I've had a career in helping others understand that making choices is a right we have – not a privilege we earn. It doesn't matter that we don't talk like others, that we use a "device" to be mobile, or that we can't complete the basic self care tasks for ourselves. We still have a right to choices.

And so now I "choose" to be with my family. To provide my mother with the love and care she needs to live out her life with dignity and the opportunity to make daily choices for herself. I choose to spend more time with my family and to take better care of myself.

I take with me the memories, laughter and lessons of the last 20 years. Thank you. Thank you all for allowing me to be a part of your lives, for teaching me and for giving me the opportunity to make a difference in our community. May God bless you and your families.

Rose A. Gilbert

Project PROMPT/Families Helping Families of Greater New Orleans

September 1986-August 2006

**Summer 2006**

**Inside this issue:**

Farewell	1
CSHS Supports Family Matter	2
Top Ten Tips for Advocates	2
Emergency Preparedness	3
Grandparents Do's and Don'ts	3
IDEA Regs	4
Partners in Policymaking	4
Operation House Call	4
LaTEACH	4
Louisiana High School Redesign	5

### Special points of interest:

- Take and Go Emergency Books are now available in our office and on-line.
- Jefferson Parish Public Schools Needs Parent of Students with Emotional Disturbance Classification for New Group.
- New Executive Director search begins.

# CSHS supports Family Matters

Families Helping Families of GNO works with Louisiana Public Health in providing a parent liaison to support other parents whose children have special health care needs. If you use CSHS (Children's Special Health Services) clinics to meet your child's special health care needs, look for FHF GNO staffer Thuy Nguyen. Thuy (pronounced Twee) is a parent of a child who has special health care needs too. And she is especially looking forward to meeting with you in upcoming clinics to see if you will help her complete a survey

for the Family Matters project. Family Matters, a grant from Bright Futures, is a project of Tufts University and Family Voices. Family Matters is hoping to learn more about the primary health and nutrition of children with special health needs. Family Matters is inviting you to consider using some of your time



while waiting to be seen in the clinic to meet with Thuy and complete a survey. If you are able to do so, Thuy will have a gift certificate for the first 5 or so participants. Whether or not you are interested in completing the survey, the next time you are in a CSHS clinic, look for Thuy. Ask her about other information, training and supports that FHF GNO can of-

**Save the Date!**  
**FHF Open House**  
Tues., October 10th, 2 - 6 p.m.  
More info coming soon!

## TOP TEN TIPS FOR ADVOCATES

Reprinted from NDSS's Web Site, [www.ndss.org](http://www.ndss.org)

Whether your advocacy work is with your child's doctors and teachers or in the halls of Congress!



1. Be an advocate not an adversary.
2. Know your audience. Everyone has a unique perspective and you need to understand the perspective of the person you are dealing with.
3. Give this person credit and praise for every great idea (even if it started out as yours).
4. Be ready, willing and able to provide

as much information as is necessary to follow through with the idea or request.

5. Put important requests in writing and provide a timeline.
6. Allow a reasonable time for requests to be processed; then follow up with phone calls and letters.
7. Bring a friend, family member or fellow advocate to appointments and meetings when you need someone to take notes, bear witness or just be there for emotional support.
8. Before a meeting or appointment, prepare a list of the points you need to make

and the questions you need to ask. Also, plan your responses to any questions or comments that you can anticipate. It's easier to stay calm if you are not caught off guard.

9. If you get what you want (which won't always happen even if you are a great advocate) express gratitude. This is true even if the person should have done it without your intervention. Everyone responds to appreciation.

10. Remember that advocacy is something we all do every day. Sometimes the issues are national, sometimes they are personal, but they are always important because they are about our kids.

## Free School Supplies

American Red Cross has donated a large amount of schools supplies to share with families in our region. If you have a child in school and need school supplies, they will be given out on a first come, first serve basis at our office.



We will continue giving out supplies for as long as they last. Please call the office at 504-888-9111 or 800-766-7736 (toll free) before dropping in to make sure we still have supplies left.



## Families Helping Families of GNO Is now accepting resumes for the Executive Director Position

Qualified applicants must be the parent of a person with a disability. They must also demonstrate an understanding and commitment to the Guiding Principles of Act 378 of 1989, an understanding and commitment to the values in the Developmental Disabilities Assistance and Bill of Rights Act 2000, the capability to hire and manage staff, manage numerous government contracts, and run a private, non-profit business. Applicant must have the ability to support staff in providing core services of information and referral, peer to peer support and education and training to individuals with disabilities and their families and a general knowledge of the special educational system and the various state agencies that provide support services to people with disabilities and their families.

To apply please mail a resume and cover letter to:

Al Hitt, 201 Evans Road, Bldg. 1, Suite 100, Harahan, LA 70123

Or email [Alhitt@bellsouth.net](mailto:Alhitt@bellsouth.net)

## Emergency Preparedness - *The Take and Go Emergency Book*

In cases of evacuation, individuals with disabilities not only need certain items, but also need to have a lot of information. This valuable information can be the difference between a smooth transition versus a very bumpy road to who knows where. Families Helping Families, The Office for Citizens with Developmental Disabilities, The ARC of Louisiana, People First of Louisiana, AARP Louisiana, Center for Disabilities and Special Needs Preparedness and Inclusion Research Institute has collaborated to develop **The Take and Go Emergency Book**. This book comes in two formats, a traditional 8 ½ x 11 inch book and a smaller 3 ½ x 2 ½ pocket size booklet that also comes with a badge case and lanyard so they can be worn around the neck.

Both documents allow you to place a picture of the person and state how they communicate, (i.e., speaking, sign language, communication device or gestures). There is a place to record all personal information, family members and contact information, other people that are important in their lives, a short history, legal status, blood type, insurance, Medicaid/Medicare, Primary and Secondary Care Physicians, durable medical equipment used, life support equipment, health conditions, medications, pharmacy number and prescription numbers, allergies, dietary needs, how they eat, likes and dislikes, what makes them happy, things that they do not like, things that make them angry or scared, how they drink, how they take medication, types of sup-

ports they receive, programs that assist them, provider agency contact information, where they go to school, if they have an IEP, related services on IEP, employer and contact information, banking information, how they understand and what people need to know to make them healthy, safe and happy. It also has preprinted numbers to state agencies in the event you cannot get in touch with local agencies.

These books are great for any individual with a disability, typical children and the elderly. Anyone wishing to receive one of these books free of charge, please contact Families Helping Families of Greater New Orleans at 504.888.9111 or email [mtaylor@fhfgno.org](mailto:mtaylor@fhfgno.org).

## Grandparents: The Do's and Don'ts of Planning for Your Grandchild with Special Needs.

*As reprinted from the Exceptional Parent Magazine's Website*

Grandparents want the best for their children and grandchildren. They often give gifts while alive, or make provisions for them after their death. Grandparents who are in a position to leave money to grandchildren often want to do something for their grandchild with special needs. They often worry about a grandchild with a disability, who may need additional assets or assistance to enjoy a good quality of life. Grandparents are sometimes told not to leave their grandchild with special needs anything because the child may lose government benefits. People are often confused as to what to do or not do. Grandparents can leave money to their grandchild(ren) with special needs. But there are very precise ways to do it. Money has to be left in such a way so that government benefits are not lost. Assets in excess of \$2,000 will cause the loss of certain government benefits for the person with special needs. If properly structured by a knowledgeable special needs attorney, the special needs trust assets will not count towards the \$2,000 SSI limits for an individual. Money should not be left to the grandchild directly, but should be left to a special needs trust. The special needs trust was developed to manage resources while maintaining the individual's eligibility for government benefits. The trust is maintained by a trustee on behalf of the person with special needs. The trustee has absolute dis-

cretion to manage the money in the trust and decides how the money is used. The money must be used for supplemental purposes only. It should only supplement, or add to benefits (food, shelter or clothing) that the government already provides through Supplementary Security Income (SSI). It must not supplant or replace government benefits. If properly structured by a knowledgeable special needs attorney, the special needs trust assets will not count towards the \$2,000 SSI limits for an individual.



**Brief Summary of Do's and Don'ts!**

- Do's:**
- 1) Make provisions for your grandchild(ren) with special needs. Leave money to the child's special needs trust. The special needs trust is the only way to leave money without losing government benefits.
  - 2) Coordinate all planning with the child's parents or other relatives. Notify the parents when you plan for grandchild(ren). Plan with others.
  - 3) Leave life insurance, survivorship whole life policies and annuities to the child's special needs trust. The special needs trust can be named as the policy beneficiary. When the insured or annui-

tant dies, the death benefit is paid to the special needs trust. The special needs trust then has a lump sum of money to be used in caring for the grandchild(ren) with special needs.

4) Consult with trained financial and legal professionals with specialties in special needs estate planning.

**Don'ts:**

- 1) Do not disinherit your grandchild(ren) with special needs. Money can now be left to a properly drawn special needs trust. It does not make sense to disinherit any of your grandchild(ren) with special needs.
- 2) Don't give money to your grandchild(ren) with special needs under UGMA or UTMA (Uniform Gift or Transfer To Minors Act). Money automatically belongs to the child(ren) upon reaching legal age. Government benefits can be lost!
- 3) Don't leave money to a grandchild(ren) with special needs through a will. Money left will be a countable asset of the child and may cause the loss of government benefits.
- 4) Don't leave money to a poorly set-up trust. Money left in an improperly drafted trust can result in the loss of government benefits.
- 5) Do not leave money to relatives to keep or hold for the child with special needs. The money can be attached to a lawsuit, divorce, liability claim or other judgment against the relative .

# IDEA 2004 Regulations Are Here!

Department of Education Secretary, Margaret Spellings has announced the final regulations to implement Part B of the Individuals with Disabilities Education Improvement Act of 2004 (IDEA) are now available. An official copy of the 1,700 page document is available now on the web



<http://www.ed.gov/policy/speced/guid/idea/idea2004.html#regulations>.

An official copy of the document will be published in the Federal Register on August 14, 2006.

## LaTEACH

### Louisiana Together Educating All Children



Louisiana Together Educating All Children (LaTEACH), promotes appropriate, inclusive education for all students. We work to make parents,

educators, the general public, and state leadership informed and supportive of research based effective practices used appropriately for each student.

LaTEACH's guiding principles are:

- We believe all students, with or without disabilities, should be provided the same opportunities to be educated in neighborhood schools

## Partners in Policymaking Now Recruiting for Class of 2007

The Louisiana Developmental Disabilities Council seeks applications from motivated, interested people who have developmental disabilities—or who are family members of young children with developmental disabilities - to become candidates for Partners in Policymaking.

The council is especially interested in persons who are not actively involved in existing organizations, but have the enthusiasm and potential to become effective advocates in the future.

Every attempt is made to select candidates who are persons with developmental disabilities and who reflect a cross section of gender, disabilities, ethnicity, and the geographic areas of Louisiana.

Candidates are asked to commit to 6 sessions (Friday - Saturday), 1 session per month for the months of January to June of 2007.

Approximately 25 applicants will be selected for each class.

If you'd like to apply to the next class, please call us at 504-888-9111 or 800-766-7736 (toll free).

as their sisters, brothers, friends and neighbors.

- We believe all students, with or without disabilities, need and should be provided with the support to learn together effectively, involving family, school and community.
- We believe all educators should be provided with the training and resources to teach students with diverse learning styles and needs.
- We believe all students, with or without disabilities, need and should be provided educational opportunities which address their individualized needs, use research based practices, result in mean-

## Operation House Call Louisiana

A new joint effort of FHF of GNO, Louisiana DHH/Office for Citizens with Developmental Disabilities, Resource Center on Medical and Dental Supports, LSU Pediatric Residency Program and Tulane/Ochsner Pediatric Residency Program, called Operation House Call, is looking for families to participate in this new program.

Operation House Call - LA will expose pediatric and family medicine resident physicians to the daily routine of parents who have a child with special needs living at home. This is a unique opportunity for parents to provide future physicians a glimpse of what life is like in your household. In an effort to educate professionals you will have a chance to demonstrate not only the extraordinary challenges which you may face as a family caring for a child with a disability, but also the natural acceptance and dignity you provide by recognizing your child as a vital, important part of your family.

If you are interested in volunteering your time and energy to share your knowledge about raising a child with special needs, please call our office at 504-888-9111 or 800-766-7736 (toll-free) for the Family Volunteer Application Questionnaire.

ingful outcomes, and prepare them for productive and satisfying lives.

- We believe all parents should take the lead through active participation and be given the training and resources to address their child's individualized needs, use research based practices, result in meaningful outcomes, and prepare them for productive and satisfying lives.
- We believe that ALL students are valued members in society and can and should become fully participating and contributing citizens.

For more information about LaTEACH or to join, please call Families Helping Families at 504-888-9111.

# Louisiana High School Redesign

Reprinted from La. Department of Education website

[www.louisianaschools.net](http://www.louisianaschools.net)

The Commission on High School Redesign was created in 2004 by the Governor, and appointed by the Board of Elementary and Secondary Education and the Board of Regents, to redesign high schools enabling all Louisiana youth to graduate from high school prepared to succeed. Thirty-six individuals representing key stakeholder groups were appointed to serve on the commission. The commission held its initial meeting on October 10, 2004, and has met regularly since that time.

In March of 2005, Governor Blanco committed Louisiana to the American Diploma Project Network, making Louisiana one of

twenty-two states pledging to prepare all high school students for college and work. The governor assigned oversight responsibility for this endeavor to the High School Redesign Commission. A key goal of the American Diploma Project is to restore the value of the high school diploma by assuring that high school standards and curriculum are aligned with the knowledge and skills needed for college and work readiness.

In May of 2005, the Louisiana Legislature passed a bill enacting the Commission in statute for the purpose of making recommendations for the development of state-wide policies, guiding principles, and programs that address the current and future

economic needs of the state and promote student success in high school and life beyond secondary education.

In August of 2005, Louisiana was selected as one of ten states to receive a grant from the National Governors Association (NGA) to support high school redesign efforts.

The Department of Education needs your help to redesign high schools across Louisiana. Please take a few moments to answer these short surveys:

[www.louisianaschools.net/lde/doe\\_par\\_fam.asp](http://www.louisianaschools.net/lde/doe_par_fam.asp) (parents and families);

[www.louisianaschools.net/lde/students.html](http://www.louisianaschools.net/lde/students.html) (students);

[www.louisianaschools.net/lde/doe\\_teachers.asp](http://www.louisianaschools.net/lde/doe_teachers.asp) (teachers);

[www.louisianaschools.net/lde/doe\\_admin.asp](http://www.louisianaschools.net/lde/doe_admin.asp) (administration);

[www.louisianaschools.net/lde/doe\\_community.asp](http://www.louisianaschools.net/lde/doe_community.asp) (community members)

## Effective IEP's and Empowerment

September 27, 2006

Presenters: **Craig Blackburn & Charlene Comstock-Galagan**

Craig Blackburn will deliver his empowering "I CAN" presentation speaking from his own perspective as a person with Down syndrome. Don't miss this chance to hear this dynamic speaker give his perspective on high expectations, inclusion and what individuals with disabilities can accomplish.

Charlene Comstock-Galagan is a consultant on inclusive education and has presented at conferences across the country.

This is a collaborative activity between Families Helping Families of GNO, Bayouland Families Helping Families and St. Charles Parish Public Schools.

The training will be held at Dougie V's Restaurant, 13899 River Rd., Luling from 8:15 a.m. to 12:00 noon.

To register to attend, please call 504-888-9111, 800-766-7736 (toll free) or email [mtaylor@fhfgno.org](mailto:mtaylor@fhfgno.org).

## Does Your Child Have an ED Classification?

Jefferson Parish Public Schools is currently under a Corrective Action Plan, which requires them to address the way they educate students with Emotional Disturbance Classifications.

If your child has an ED classification, attends a public school in Jefferson Parish and would like to participate in an advisory committee, please contact Laura S. Nata with FHF at 504-888-9111 or 800-766-7736 (toll free). Meetings will be on the east and west banks.



## Voting Rights

August 17, 2006

3 - 5:00 p.m.

Old Metairie Library

2350 Metairie Rd., Metairie

## WE WANT YOU!

The Secretary of State's office, along with the Advocacy Center, is having a meeting on your voting rights and a demonstration of the new accessible voting systems in your area. Many people with disabilities can not vote without assistance. Come by, try out the machines and learn more about your voting rights! For more info or to request accommodations, call Stephanie Patrick at 1-800-960-7705, ext. 143.

## Buddy Walk

Mark Your Calendar for October 22, 2006

**The Down Syndrome Association of Greater New Orleans' 4th Annual Buddy Walk will be at LaSalle Park, Next to Zephyr Field on Airline Drive in Metairie. Registration opens at 7:30 a.m. Walk begins at 9:00 a.m. and the party follows after the walk! Join in for great food, lots of fun, family and friends. Entertainment by Papillion and The Top Cats. There will also be Robear's Snowballs, Sauce Picante, Jambalaya, and more. Door prizes and Sparky the Fire Dog. Information booths from area non-profits with giveaways and children's activities.**



Of Greater New Orleans

201 Evans Road, Building 1, Suite 100  
Harahan, Louisiana 70123  
Phone: 504-888-9111  
Fax: 504-888-0246  
E-mail: info@fhfno.org

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• This newsletter is printed in part through a grant from the Louisiana Developmental Disabilities Council, Louisiana  
• Department of Education, Jefferson Parish Human Services Authority and Metropolitan Human Services District.  
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The Jefferson Council on Aging is pleased to announce the opening of its Aging and Disability Resource Center (ADRC). In partnership with the Governor's Office of Elderly Affairs, and the Department of Health and Hospitals and in conjunction with the statewide initiative LouisianaAnswers.com, the center will link adults living with disabilities, senior citizens, and caregivers to the information they need to improve their health, independence, and quality of life.

LouisianaAnswers.com serves the parishes of Jefferson, Orleans, Plaquemines and St. Bernard.

For additional information, please call 504-888-5880 or 800-635-1437 (toll free).

## LOUISIANA CITIZENS FOR ACTION NOW

*Advocating for Louisiana Citizens with Developmental Disabilities*

LaCAN is a statewide grassroots network of individuals and families who have worked together since 1988 advocating for a system that supports individuals to live in their own homes rather than having to move to a facility to receive needed services. Specifically, they have advocated for implementation of Louisiana's Community and Family Support System Plan.

Regional LaCAN teams include parents, individuals with disabilities and parents. These members are notified by telephone trees to contact state agency officials, legislators or the Governor when necessary.

For additional information or to join LaCAN please contact us at 504 -888-9111.

## LaDisability Talk

### A Statewide Talk List

#### What is LaDisability Talk?

An email talk list from Project Prompt/Families Helping Families of GNO to help families of people with disabilities and their advocates in Louisiana share information, resources and support.

#### What's a talk list?

It is a way for email users to be in a group with others who have similar interests.

#### Who should join?

Parents of children with disabilities, self-advocates, and advocates for people with disabilities in Louisiana.

#### How do I join?

Just send an email to: fhfprompter@yahoo.com or LaDisability-Talk-subscribe@yahoogroups.com.