

Advocating Daily



EDUCATING AND EMPOWERING INDIVIDUALS WITH DISABILITIES

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Spring 2014

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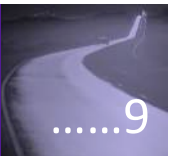
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Opinions contained herein do not necessarily represent those of the funding sources, and no endorsement should be inferred.

LaCAN members from around the state approaching the steps of the Louisiana State Capitol in Baton Rouge for the annual Disability Rights Rally on March 19th, 2014 to advocate for expansion of the New Opportunities Waiver [NOW] Services.

FHF-SELA Staff:

CAROL'S CORNER

Carol F. Calix
Executive Director

Alex Abend
Projects Coordinator

Aisha Johnson
Transition Advocate
(STATE DEPARTMENT OF
EDUCATION)

Elizabeth Springs
Information and Referral Specialist
(METROPOLITAN HUMAN
SERVICES DISTRICT)

Lyntrell Ratleff
Office Assistant
(METROPOLITAN HUMAN
SERVICES DISTRICT)

Maria Chriss
Office Assistant
(METROPOLITAN HUMAN
SERVICES DISTRICT)

Shay Hunter
Community Outreach Specialist
(EARLYSTEPS)

Tiecha Keiffer
Data Entry Specialist

Tracy Jones
Office Assistant
(METROPOLITAN HUMAN
SERVICES DISTRICT)

Ricki Ainey
LaCAN Leader

Jane Rhea Vernier
Intern
(TULANE SCHOOL OF SOCIAL
WORK)

A LETTER FROM THE DIRECTOR:

Unemployment is a hot topic these days...

But unemployment within the disability community has always been high. This trend will continue unless we are able to break down some of the barriers that prevent individuals with disabilities from seeking and keeping employment.

There are issues to consider: Who is going to provide transportation? Will he/she be exposed to the public where, without supervision, someone can take advantage of him/her? Will he/she make bad choices that will get him/her into trouble or hurt? Sometimes it is just easier to keep the individual with a disability at home watching TV or playing video games.

Other times, parents fear that employment will cause them to lose their Social Security check and any waiver services.

For employers, many may fear that when they hire a person with a disability, the person may become a liability to the company.

Whatever the reason/excuse is, we want to know what you think. Please go to <https://www.surveymonkey.com/s/SNPW27R> and complete our survey. This is the first of a three-part process to be able to present to families, caregivers and providers about employment in our region and what we can do to overcome some of the barriers. Once we have gathered information from the surveys, we will hold a focus group to discuss everyone's answers and to try to isolate items that are of the utmost concern to our families. Then, in June, we will host our annual Metropolitan Human Services District Family Forum and, you guessed it, it will be all about employment.

Don't have access to a computer? Call us, we can read the questions to you. If you are interested in being a part of the focus group, call Elizabeth Springs in our office at (504) 943-0343 and we will reserve a spot for you. A small stipend will be given to parents who participate in the focus group.



Families Helping Families of Southeast Louisiana receives partial funding from Metropolitan Human Services District, the State Department of Education, the Louisiana Developmental Disabilities Council, Family to Family Health Information Center, Amerigroup, Xerox Corporation, LSU Health Science Center, and Early Steps

Summertime Fun

FROM THE LOUISIANA FAMILY TO FAMILY HEALTH INFORMATION CENTER

By Julie Folse
Program Supervisor

With the summer months almost upon us we are all looking for ways to keep our children active and from hearing the dreaded words "I'm bored." But parents of children with disabilities have to put forth extra effort to find things for their children to do. Children with disabilities require activities that will meet their specific needs or limitations but will also stimulate them while remaining fun. There are several fun activities you can do to help build motor skills and learning skills while including siblings or friends.

Bunny Catch (A twist on the classic Hot Potato game): Gather children into a circle for this game, which involves balls in two different sizes, one larger and one smaller. The bunny is the small ball, and the children should pass it from one child to the next in the circle. When the bunny gets halfway around the circle, introduce the larger ball, or the farmer. The farmer should start in the same direction, but can change directions as needed. The bunny ball only travels in the same direction. The goal of the game is for the farmer to try to catch the bunny, and for the bunny to try to get away. Read more:

http://www.ehow.com/list_6329522_games-kids-disabilities.html#ixzz2yxnscl0R

What Is It? Put different items with various textures into individual bags, such as soap, a stick of gum, a candle, tissue, a leaf or a sock. Sit all of the children down in a circle and pass out the bags. Each child should reach into a bag and guess what they are holding. If they guess incorrectly, they are out of the game. Pass the bags around from player to player until only one child remains- the winner! Read more:

http://www.ehow.com/list_6329522_games-kids-disabilities.html#ixzz2yxoc4qqK

Sticker Story: Layout several sheets of stickers that include various themes and shapes and a blank sheet of paper with two to three lines drawn on it. Have your child tell a story using only the stickers on the paper provided. Then you must try to figure out the story based on the stickers they used.

Rock painting: Have your child pick several rocks from around your home. Then have your child paint and decorate the rocks. What a fun idea!

Scavenger Hunt: Make a list of random things in or outside your home and see how many your child or group can find. This is a fun game that uses things already in your home and can involve hours of play!

Depending on your child's abilities and personality, different activities may or may not be the best for them. Sometimes the simplest and easiest ideas work the best. These were just a few ideas of simple and easy things you can do. Remember be creative and have fun!

Julie Folse is the mother to 6 year old Alivia and 4 year old James. James is diagnosed with Tetralogy of Fallot, Hypospadias, Imperforated Anus, and Speech Delay. For more information on Family to Family Health Information Center, Family Voices, and health information for children with disabilities please contact Julie at f2fhic@gmail.com or (985) 447-4461.

FHF-SELA Board of Directors:

Molly Sullivan
Interim-Board Chairman

Claudia Smith, BSM
Secretary

Jim Durbin, Jr., CPA
Treasurer

Donnica Conway-Strawder

Everett Henderson

Kim Jones

Willie Martin

Valerie Read

Brenda Valteau

Georgette K. Wallace, MPA, MS

Mike Yazbeck

Are you interested in serving on the FHF-SELA Board? Please call Carol Calix at (504) 943-0343 ext. 204 or email ccalix@fhfsela.org.

Our board meetings are open to and welcome the public.

Meetings are held at 6pm on the 3rd Monday of even numbered months.

Remaining scheduled 2014 Board Meetings are April 21, June 16, August 18, October 20 and December 15.

Meetings are held in the 3rd floor conference room.
7240 Crowder Blvd
New Orleans, LA 70127

Families Helping Families of Southeast Louisiana Services and Programs

FHF of SELA is a 501(c)3 non-profit resource center for individuals with disabilities and their families. For more information about the services and programs we provide, please call 504-943-0343.

PROGRAMS

ALL AGES

Louisiana Deafblind Project ♦ A statewide technical assistance and dissemination project, which provides technical assistance, training, and information to enhance services for children and youth 0 – 22 who have the diagnosis deafblindness.

LA Citizens for Action Now (LaCAN) ♦ A statewide grassroots network for individuals and families advocating for a service system supporting individuals with disabilities to live in their own homes rather than a facility.

0-3

Early Steps Community Outreach Specialist ♦ The specialist visits hospitals and clinics with information about Early Steps for hospitals, clinics and parents who have children who may exhibit developmental delay.

4 – 14

Education Advocate (Funded by the State Department of Education) ♦ Advocates for all students to be in regular education and community settings to ensure full and valued membership in society, provides workshops, presentations, and one-to-one support. Advocates for children to be educated in the Least Restrictive Environment and educates parents on being their child's advocate.

The Prism Project of Greater NOLA: Roux-Roux Productions (TPP of GNO) ♦ A performing arts program for children aged 6-14, with and without special needs. TPP of GNO teaches children dance, music, and theater, creating an original performance.

15 – 22

Career Symposium ♦ A multi-faceted workshop for students with disabilities, their families, and teachers to better prepare students with disabilities to have meaningful careers after high school.

Transition Advocate (Funded by the State Department of Education) ♦ Trains, educates and empowers families

and professionals to develop Individualized Transition Plans.

22 +

People First of NOLA ♦ An adult advocacy group for people with disabilities ♦

SERVICES

INFORMATION AND REFERRAL

- ♦ Information and referral for evaluations, medical services, Medicare, Medicaid, and Crisis Intervention ♦
- ♦ Information on community programs, services and opportunities ♦
- ♦ Educational materials, disability-friendly apps, and publications ♦
- ♦ Internet and personal resources across all three parishes ♦

EDUCATION AND TRAINING

Workshops on caregivers, transition, education, IEP/504, school and family partnerships, communication, healthcare, advocacy and more.

Register for our latest workshops online or by calling 504-943-0343.

PEER-TO-PEER SUPPORT

Continuous information, guidance, and support from our employees who are parents, siblings, and self-advocates.

OUR VISION

We envision a region where people with disabilities live and are fully included in school, work, and recreational activities.

OUR MISSION

Families Helping Families of Southeast Louisiana's mission is to educate and empower individuals with disabilities, their families, professionals, and communities by providing resources, training, and family-to-family support.

APRIL

SUN	MON	TUES	WED	THURS	FRI	SAT
		1	2	3	4	5
Pg 10						
6	7	8	9	10	11	12
						TPP Show
13	14	15	16	17	18	19
	People First BESE				OFFICE CLOSED	
20	21	22	23	24	25	26
	FHF-SELA Board Meeting		BESE			
27	28	29	30			

Pg 3

Diploma Pathway
on Pg 11

4/28 and 6/30 are
Sensory Friendly
Family Night @ LA
Children's Museum
4:30-6:00pm

Workshops every
Mon, Wed & Fri
10:00-11:30am IEP
beginning to end

MAY

SUN	MON	TUES	WED	THURS	FRI	SAT
				1	2	3
					TPP DVD order due date	
4	5	6	7	8	9	10
		GIVENOLA DAY				
11	12	13	14	15	16	17
MOTHER'S DAY						
18	19	20	21	22	23	24
		People First Meeting				
25	26	27	28	29	30	31
	OFFICE CLOSED		BESE			

Pg 10

Pg 11

JUNE

SUN	MON	TUES	WED	THURS	FRI	SAT
1	2	3	4	5	6	7
	End of legislative session					
8	9	10	11	12	13	14
					RAC meeting	
15	16	17	18	19	20	21
FATHER'S DAY	FHF-SELA Board Meeting	People First BESE				
22	23	24	25	26	27	28
28	30					

Pg 3

Pg 11

Pg 10

June Forum
Date TBD

SELF-ADVOCATE SPOTLIGHT

“LET’S GO OUT THERE AND CHALLENGE LIFE”

Dewain Baldwin

By Elizabeth Springs and Jane Rhea Vernier
FHF-SELA Staff

Dewain Baldwin is a busy person with an exuberant perspective on life. Dewain, 28, is a Delgado student and works two jobs. “I love helping people, love going out there and making money,” he says, about why he is so active. He likes living with his mother “helping out with everything at home.” But his long-term goal is to have a home of his own. Dewain enjoys going to new places and taking on new jobs so that he is always learning new things.

Dewain is employee of the year, and a manager at The Arc of Greater New Orleans where he has been working for two years. His work includes landscape projects in City Park. As a manager, he is responsible for instructing other team members about how to cut the grass.

Dewain says he likes riding mowers all day and being outside, but that he prefers his second job at the Superdome. In his position as a security guard, which he has also held for about two years, he gets to be in the air conditioning and he gets to see all the events. But the real reward for Dewain is being around people and activity.

Dewain attended St Michaels Special School for high school. Dewain is now studying computers and art at Delgado. He says he likes to draw and put his work up at home in his room. “Some I finish, some I don’t finish... it’s something that I love to do,” says Dewain modestly, regarding how good he is.

Dewain has an irrepressible confidence in himself, and believes this attitude can work for other people. He doesn’t like it when people use excuses



and judgment of what other people think to hold themselves back. “If you don’t love yourself, no one else will,” says Dewain. His brother and his sister are Dewain’s role models for what he wants to get out of life. His brother told him all he needed to do to get what he wants is to work hard at it. “If my brother can do it, I can do it, too.” Dewain knows that the support of people who believe in him are why he is where he is today.

“If you want to get somewhere, you’ve got to move forward with the whole program,” Dewain advises others who want to make a change in their lives, like getting a new or better job. “I say in the mirror, ‘I believe in myself,’ three times a day... when other people see your energy, they might just hire you because they see what you are willing to do.”

Dewain says, “if you are scared of failing, you are never going to get what you want...The more you enjoy the process, the more fun it’s going to be. You can’t hold back- once they see the real you, they are going to hire you.”

Dewain sums up his perspective on life, “let’s stop worrying about what other people think, let’s stop whining, and let’s go out there and challenge life.”

TEACHER SPOTLIGHT

My name is Caileen Coleman,

and I am a Special Education teacher at Carver Senior High School. This is my second year teaching three amazing students with significant, multiple disabilities. The focus in my classroom this year has been transition and what that will entail for each student. I am currently organizing the first ever Transition Vision Building Week for high school students over 18 years old in the Recovery School District.

This weeklong learning opportunity in May will help parents and students see in person what transition means for individuals with disabilities in New Orleans. Each day will focus on a different element of transition, including living arrangements, employment opportunities, advocacy, recreational activities, and group reflection.

Providers, agencies, and organizations that serve adults with disabilities will be participating in the experience; this includes AcME, The Arc of Greater New Orleans, Magnolia Home, Padua Community Services, Louisiana Rehabilitation Services, and Families Helping Families.

The Transition Vision Building Week is important because many scholars and parents unfortunately do not know what is available for people with disabilities after high school. By

providing targeted outings in which parents and scholars visit various programs and experience services offered in New Orleans, they will be able to build a vision for their own ideal transition. Knowing exactly what is out there and meeting



others in similar situations will assist parents and scholars in their expectations and goal setting for transition planning. Parents and scholars need to have choice in what their specific transitions look like, and that choice must be informed by opportunities available to them. The Transition Vision Building Week will inspire and motivate students and parents, and it will ensure that more adults with disabilities have informed visions of meaningful, productive, and enjoyable futures.

Stipends Financial Assistance for Conferences in Louisiana



Financial assistance is available to parents of children with developmental disabilities and people with developmental disabilities who would like to attend workshops and conferences. Please visit the website and/or call the agencies that are hosting the event if you are interested in attending or see if this is something you would benefit from. If you want to attend and need help with the cost of registration, hotel, and/or mileage, please call us for a **Stipend Application**. Funds are limited, so we ask that you notify us of your request as early as possible.



(504) 943-0343

•
ccalix@fhfsela.org
or
www.fhfsela.org



Thank you to all who participated in the second

TRANSITION ACADEMY!

Parents and educators who participated in Transition Academy on Saturday, March 15th explored transportation, meaningful employment, Social Security, and more in the post education transition process. It was an amazing success!



There's No Place Like Home

A Musical Adventure
DVDs On Sale!



DVD's on sale for \$10.00

Place your order **before May 2, 2014** by emailing aabend@fhfsela.org. Please include your name, address, phone number, total amount and payment method. Please make checks out to Families Helping Families of SELA. Please make credit/debit payments over the phone or in person and be aware of the service charge.

Want More? Visit www.fhfsela.org and check out The Prism Project of Greater NOLA for videos, pictures, and volunteer opportunities.





The 2014 king and queen Willie Martin and Tracy Jones at the *People First Mardi Gras Ball*!

People First of NOLA

If you are an adult with a developmental disability and want to learn self-advocacy skills, come join People First of NOLA!

People First of NOLA is...

- A self-advocacy group run by people with disabilities, for people with disabilities
- Where people learn to speak for themselves about decisions they make.
- Where members can connect with others in the community, nation, and world
- Where members learn about their rights and responsibilities as citizens of the US



People First of NOLA meets every 3rd Tuesday of the month at 4:30pm

May 20, June 17

New Orleans Healing Center

2372 St. Claude Ave

New Orleans LA 70117

The LaCAN Adventures

The LaCAN Adventures chronicles advocacy efforts of individuals with disabilities and their families for a service system supporting individuals with disabilities to live in their own homes rather than a facility. We are looking for people in need of waiver services to contact our legislators with compelling stories.

Tell us your adventure! Contact Rickii Ainey at lacanregions1and10@yahoo.com today!



ASK AN ADVOCATE

Dear Advocate,

I was speaking about a friend who refers to herself as autistic, and was corrected to say that, "she has autism." My friend is an outspoken self-advocate, but the person who corrected me said that, "she has autism," is more politically correct. How do I know what is right to say when?

Sincerely,

Politically Confused

Dear Politically Confused,

You have found your way to the debate about People First Language and Disability Identity First Language.

People First Language is an important part of advocacy because it enforces the similarities between people with and without disabilities, rather than the differences. People First Language puts the person before the disability, and strives to correct stereotypes and negative attitudes about disability. Those who prefer People First Language are fierce advocates and can be rigorous about using it everywhere. You can find more about People First Language at *Disability is Natural*,

<http://www.disabilityisnatural.com/explore/people-first-language>

Identity First Language affirms that a person and disability are as inseparable as a person and race or

ethnicity, as inseparable as a person and gender or sexual orientation. Identity First Language uses capital letters to affirm Disability and Autism as cultural identifiers. Identity First Language also strives to correct stereotypes and negative attitudes about Disability. Those who prefer Identity First Language do not believe that Disability is paramount to disease or disorder, and can be quite vocal against People First Language. You can find more about Identity First Language at the *Autistic Self-Advocacy Network*, at

<https://autisticadvocacy.org/identity-first-language/>

You can find more about how to write about disability at the *National Center on Disability and Journalism* <http://ncdj.org/style-guide/>

When you do not know how a person or their family refers to disability, or if you are speaking generally, using People First Language until you learn otherwise is a safe plan. However, because you know that your friend considers her Disability to be her identity, you should honor her identity and say that she is Autistic. You will have to decide which side of the debate you agree with for yourself! These tools should help you navigate the debate between People First Language and Identity First Language whenever and wherever you encounter it.

Sincerely,

Jane Rhea Vernier

Self-Advocate



LaTEACH
Louisiana Together Educating ALL Children

Teaching Louisiana the LaTEACH Way

LaTEACH Coordinator: Vacant Position

www.lateach.org

Attend a BESE Meeting and Advocate! May 28th, June 17th, June 18th

All meetings are held at the Claiborne Building (1201 N. 3rd Street) in Baton Rouge, Louisiana.

What can BESE and Legislators do? Ensure diploma pathways for all students, make education funding equitable to all students based on student needs, and be accountable based on maximizing student potential. For more information go to www.LaTeach.org

PARENT ADVOCACY

APRIL IS AUTISM AWARENESS MONTH

What if Autism Prevalence was 1 in 10 instead of 1 in 68?

By Karen Scallan

Parent Advocate

April is Autism Awareness month and we are all hearing about the increased frequency of autism diagnoses among our children. The CDC now says 1 in 68 children have an autism spectrum disorder or ASD. What we do not hear is how often it occurs in people with other genetic and chromosomal disorders. According to a 2008 article in the *Journal of Applied Research in Intellectual Disabilities*, *Autism symptoms in toddlers with Down syndrome: a descriptive study*, the authors indicate the prevalence of autism in children with Down syndrome is potentially as high as 1 in 10. And we know there is a higher prevalence of Autism co-occurring in other chromosomal abnormalities as well. Families of children who have been diagnosed with Down syndrome (Trisomy 21) and Trisomy 13, Angelman Syndrome, Fragile X, and Rett Syndrome particularly need to be aware of this potential increased prevalence and so do medical professionals.

For children with Down syndrome, it is very common to see symptoms of Autism present in different ways (ex. increased social ability, later onset of "Autistic" symptoms). This difference can delay identification and treatment if professionals are

not trained to diagnose Autism in children with co-occurring disorders. And, unfortunately, a delayed diagnosis is delayed progress and support. Another potential delay in diagnosis can come from the tendency to avoid putting "another label" on a child or when parents and professionals attribute autism-related behaviors to intellectual delay. Other difficulties in diagnosing Autism as co-occurring in a child with chromosomal abnormalities include lack of good diagnostic tools for this



population and lack of professionals trained to diagnose Autism as a co-occurring disorder.

Parents need to be sure their children with Down syndrome and other genetic disorders are being screened appropriately for Autism. According to the American Academy of Pediatrics, Autism

screenings should start at 18 months and continue through age five. This is vital for proper and appropriate supports to be in place and appropriate treatment decisions to be made. Professionals need to be aware that if it is appropriate, then diagnosis should be made and not avoided. We would not hesitate to add a "label" of a heart condition if that were appropriate. Autism diagnosis should not be treated any differently.

When Down Syndrome and Autism Intersect: A guide to DS-ASD for Parents and Professionals, Margaret Froehle, R.N. & Robin Zaborek

Journal of Applied Research in Intellectual Disabilities, Autism symptoms in toddlers with Down syndrome: a descriptive study, Hepburn, S., Philofsky, A., Fidler, D., & Rogers, S. (2008).

Karen Scallan is the parent of a 13-year-old son with Down syndrome and Autism. She is a parent advocate, advocating for systems change, family centered service systems and self-determination of individuals with developmental disabilities in Louisiana. She is also author of a blog: Parent Perspectives on Managed Care and Long-Term Supports and Services. She can be reached at kcscallan@gmail.com.

GIVE NOLA DAY

ONE DAY TO GIVE AS ONE
MAY 6, 2014 • MIDNIGHT TO MIDNIGHT



Give \$10 or more through
www.GiveNOLA.org
on Tuesday, May 6th and
your donation will receive
a little lagniappe!\$

Hosted by
GREATER NEW ORLEANS FOUNDATION
For a vibrant region.

THANK YOU TO OUR SUPPORTERS!

MAJOR DONORS

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Ball State University Foundation	Harrah's Casino	Salads Galore
Donnica Conway	Everett Henderson	Claudia Smith
Crescent Vans	Dr. Janice Janz	St. Bernard Volunteers for Family and Community
The Dávila & Canuto Family	Alvin Jones	Brenda Valteau
	Brenda A. Martin	

FHF of SELA is a 501(c)3 non-profit organization. We rely on contracts with organizations, partnerships with community groups, grants, and private donations. Through these incredible organizations and people, FHF of SELA is able to provide free services and programming to families and professionals across Orleans, Plaquemines, and St. Bernard Parishes. It is all thanks to these supporters and the anonymous donors that enable our organization to assist thousands of families across the Greater New Orleans Region achieve education and empowerment.

GRANTS

Amerigroup
The Davis-Molony Fund
The Frost Foundation
The Louisiana Bar Foundation
**The New Orleans Jazz & Heritage
Foundation**
Xerox Corporation

MAKE A DONATION TODAY!

\$5 connects families without internet to accurate resources

\$10 provides a student with a disability tools for a career

\$30 covers the cost of participating in The Prism Project of Greater New Orleans

\$72 enables two adults with disabilities to become empowered self-advocates

\$150 allows a child with special needs to attend summer camp

Your donation could help families of people with special needs connect with accurate resources, provide recreational opportunities to children with special needs, teach parents or people with disabilities self-advocacy skills, or provide a student with a disability the means to a dream career.

Thank you for your support!

All donations are tax-deductible

You can make a donation online by clicking Donate at www.fhfsela.org

Scan the QR Reader

OR



Mail in your donation with the form below to

Families Helping Families of Southeast Louisiana
7240 Crowder Blvd. Suite 202
New Orleans, LA 70127

Yes, I would like to donate and learn more about Families Helping Families of Southeast Louisiana!

Name: _____	Address: _____
Phone: _____	City, State, Zip: _____
Email: _____	Parish: _____
Relationship: <input type="checkbox"/> Parent <input type="checkbox"/> Sibling <input type="checkbox"/> Self-Advocate <input type="checkbox"/> Professional <input type="checkbox"/> Family Member <input type="checkbox"/> Donor	
Please add me to your mailing list: <input type="checkbox"/> Yes <input type="checkbox"/> No	
I would like to donate:	
<input type="checkbox"/> \$5 <input type="checkbox"/> \$10 <input type="checkbox"/> \$30 <input type="checkbox"/> \$72 <input type="checkbox"/> \$150 <input type="checkbox"/> Other _____	
I would like to volunteer or apply for an internship: <input type="checkbox"/> Yes <input type="checkbox"/> No	
I would like information about: _____	



Still Waiting for Waiver Services?

Join LaCAN NOW!

LaCAN (Louisiana Citizens for Action Now) is a statewide grassroots network of individuals and families who have worked together since 1988 advocating for a system that supports individuals live in their own homes rather than having to move to a facility to receive needed services.

MAKE A DIFFERENCE! JOIN LACAN!

www.lacanadvocates.org

MAKE A DIFFERENCE!

JOIN LACAN!



LaTEACH (Louisiana Together Educating All Children) is a grassroots network of individuals that believe all children should have the opportunity to be educated with their typical peers in a typical classroom.

LaTEACH has made great strides this year, but we still need **YOU** to help make a difference in improving education for our children with disabilities.

PLEASE CONTACT
www.lateach.org



What is LaDisAbility talk?

It's an email talk list from Louisiana Parent Training and Information Center/Families Helping Families of Jefferson to help families of people with disabilities and their advocates share information, resources, and support.

What's a talk list?

It's 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 of people with disabilities in Louisiana

How do I join? Just send an email to:
fhhpromter@yahoo.com or

LaDisabilityTalk-subscribe@yahoo.com

FREE-FREE-FREE

Like us on Facebook at www.facebook.com/FHFofSELA follow us on Twitter @FHFofSELA & Pinterest FHFSELA to stay up-to-date on all exciting events, articles of interest, links to other advocacy groups, information on trainings and more!



ADDRESS SERVICE REQUESTED

FHF of SELA

7240 Crowder Blvd.
Suite 202
New Orleans, LA 70127

Office: (504) 943-0343
1-877-243-7352
Fax: (504) 940-3242
Email: info@fhfsela.org
Website: www.fhfsela.org

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