Newsletter
July – September 2019

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Families Helping Families of Northeast Louisiana, Inc. is a family directed resource center whose mission is to provide information, referral and peer to peer support to individuals with disabilities and their families.
Awaken My Heart

As a mom, hearing any kind of diagnosis regarding your child can be very traumatic. For me, I heard it twice from two different doctors, but at the same time I was relieved to know what exactly was going on WITH her. It was only after a dear friend who taught Hannah suggested we have her tested THAT WE did that...she was eleven years old. For years I knew something was off, but it was finally at that age was I able to hear and receive what the doctors had to say. It was at THIS point we got connected to our local Families Helping Families of Northeast Louisiana. They were truly a “God-send” for us...they walked with us and supported us like a family during a very difficult time in our lives. Things had been extremely difficult with Hannah and if you know any one that has been diagnosed on the Autism Spectrum, you know every child is different and the severity of the diagnosis varies. Hannah, at the time was diagnosed with Asperger’s and struggled as a child to speak, carry on conversations, make friends, process emotions, struggled with clothing and food textures and would have meltdowns like I have never experienced. HANNAH ALSO STRUGGLED WITH BEING BULLIED AT SCHOOL. She eventually would start cutting as a way to deal with the emotional pain and ultimately attempted suicide while attending a local school. Another hardship that may have contributed to Hannah’s emotional issues could have been tied to her being sexually abused by a friend of the same age and gender around 9 years old.

When we finally got a diagnosis ON HANNAH I had to re-learn how to parent her. I am sure many of you that are reading this would do a lot of things differently as a parent! I remember when she was around the age of three sitting at my house crying AND wondering why God gave her to me, because it was difficult then...but I am so thankful for her and what she is doing now. For our family, our faith has had a huge impact on how we view and treat Hannah and played an important role in how the Lord has touched her. It was only after a spiritual encounter at the age of thirteen that an interest in music came about. Hannah had never played an instrument or sang BEFORE HER SPIRITUAL ENCOUNTER. She came to me one day and said she was interested in playing the guitar, so we got her a guitar and she began to teach herself from YouTube videos until we got
her professional lessons. Later on my husband Whit, who would stay up late and study for seminary, mentioned to me that he heard her sing one time and that she didn’t really sound all that bad. I literally looked at him and laughed and said whatever because I had never heard her sing a day in her life. One day, I happened to be cleaning the upstairs bathroom and heard her sing—the only thing I could say to her was that she didn’t sound that bad. I truly was in shock.

For our family and especially Hannah, faith and music has been instrumental in how God has transformed her life. Does that mean she hasn’t had struggles? No. Friendships have still been a challenge for her and we still have to guide her in certain things that really most kids her age are aware of. High school took a little longer, and that is ok. Her high school years looked a little differently than most, and that is ok. In fact, she just obtained her Hi-Set certificate and finished her high school equivalency! Autism is part of her story. Faith is part of her story and JESUS CHRIST has used music to transform her life and open doors that we would have never thought would have opened years ago. Hannah now plays not just the guitar, but the piano as well. She has sang hundreds of times over the past few years, and has traveled all over the world—praying for people and sharing her love of music with others. She has been to Honduras several times, Peru, Nicaragua and Kenya AFRICA—all being used to lead worship. She just got back from King’s Camp in MerRouge leading worship for the junior high camp and SHE continues to help lead worship in other venues LIKE CELEBRATE RECOVERY AT FBC RAYVILLE.

Over a year ago she went to Nashville and recorded four original songs for her first EP and just recently that project was finished and went live! I believe no matter the disability a person has, their life is precious and they can and do have an impact on our society in a positive way. The compassion my family has toward the disability community would not be what it is had it not been for Hannah. She in her own way is making a difference in the lives of others and in turn has impacted our own family for the good. It has been really hard at times, and we have had a lot of prayer and counseling as a family, but the good far outweighs the bad. Children with any kind of disability face challenges that most kids do not—and the challenges do not exclude their family. As each day goes by I know that Whit and I are Hannah’s best advocate. You as a parent are your child’s biggest cheerleader and advocate, because no one loves them like you and you want what is best for your child or loved one just like I do.

Hannah is on all digital outlets such as Spotify, ITunes, Amazon Prime Music, YouTube, CD Baby and more. Here are the links: [https://music.apple.com/us/album/awaken-my-heart-ep/1469814552](https://music.apple.com/us/album/awaken-my-heart-ep/1469814552) 

The “summer slide” has nothing to do with a fun summer pastime. Instead, it’s a term used to describe the tendency for students to decline in achievement gains during the summer months when school is not in session. This phenomenon is especially prominent among students from low-income families who often lack access to books over summer break.

Luckily, there are many ways to prevent the summer slide. Giving children access to books plays a critical role in warding off summer learning loss. When students keep reading, they keep learning.

Here are 7 tips for parents and caregivers to help keep children engaged in reading during the summer months:

1.) Create a fun reading space
Set up a tent or create a reading fort. Add comfy pillows, bean bags and blankets along with a basket of books to make a fun, relaxing spot for reading. The possibilities are endless.
2.) Make a reading routine
Set aside a specific time each day to dedicate to reading. By making it a priority, you relay the message that reading is important. Make time to read together in addition to creating time for children to read on their own. A nighttime reading routine can help children associate reading with relaxing.

3.) Be a role model
Get caught reading! Children are known to model the actions of adults they love. When they see you enjoying a good book, they will follow your lead. Also, be a role model by reading aloud to your child no matter their age.

4.) Ensure reading materials are readily available
Make books easily accessible in the most used rooms of your home and carry them with you everywhere. Keep selections in your car. It's also helpful to carry a bag of books for doctor visits, shopping trips, and long waits.

5.) Make reading an adventure: Visit libraries, bookstores, and take field trips
Take your child to your local library or bookstore. Picking out a book can be just as much fun as reading one. Sign up for a library card and take advantage of summer reading programs at your local public library. Feeling extra adventurous? Try a reading-inspired field trip! For example, if you read a book about dinosaurs, plan a visit to a local museum to learn more about them. Or, if you read a book about flowers, visit a local botanical garden.

6.) Encourage choice
Reading should be a choice not a chore. Allowing your child to choose the books they read gives them a sense of control. Graphic novels, magazines, nonfiction and newspapers should also be options in reading for pleasure. Allowing choice in reading materials goes a long way in raising life-long readers.

7.) Introduce your child to series
A book series can help keep reading interest high by keeping the “what happens next?” factor engaged. Series also address the problem of stalling between books because it eliminates the problem of figuring out what to read next.

Remember, the secret to preventing summer slide is to keep learning all summer!
Special Needs The Positives of Going Back to School for Children with

A post by AngelSense, a GPS & voice monitoring solution designed for children with special needs.

Can you believe it’s back to school time already? For some parents this time of year is all about finding a coping strategy and mastering deep breathing exercises. We like to take a different approach. In fact, this is our favorite time of year because even though it’s filled with changes, it’s the perfect opportunity for you to bond with your child.

![Image of a child](image)

Special needs parenting can be challenging, but it isn’t without its rewards. Instead of focusing on the difficulties and daily struggles, this is the time to celebrate your child’s milestones and to acknowledge the fact that your little one is growing up. See this an opportunity and you won’t have to try hard to put a positive spin on this new stage in your child’s life.

Here are five ways to turn back to school time into something positive and memorable.

1. Make preparing for school fun
All kids struggle with changes, and special needs kids are no exception. The transition from the summer holiday to the routine of school can be stressful and unsettling. Some parents recommend creating a ‘transition’ book to help kids adapt more easily to the new environment.

The idea is to fill the book with drawings and pictures from school. Ideally this should be updated daily to include a variety of snapshots from the classroom. It’s important that parents review the book with their kids. This will reduce any anxiety about the new environment and will quickly help establish a routine.

Various studies suggest that rehearsing hypothetical situations beforehand reduces anxiety and helps special needs kids cope more effectively. Parents can create what are known as ‘social stories’ with their kids where they visually represent stressful situations like recess, interacting with others and not interrupting using drawings, photographs or cutouts. If you’re looking for some useful social story resources, [here](#)’s a great place to get started.
2. **Make your little one feel empowered**
One way to relieve any anxiety your child may be feeling about going back to school is to make sure you purchase all school supplies and new clothing beforehand. This alleviates any last minute stress and will give your child a sense of control. It will also help prepare your child mentally for the new school year.

Ideally children should be actively involved in the process as this will help them feel empowered and grown-up. This is also the perfect opportunity to work on developing your child’s sense of self and critical thinking skills. You could, for example, get your child to choose their own clothing or school supplies. For parents looking to teach their kids to pick out the appropriate clothing, this is an invaluable resource.

3. **Get your child excited about learning**
Your attitude matters. Not only will your child pick up on how you’re feeling, but also they’re likely to respond accordingly. The important thing is to remain calm and express enthusiasm about the new school year. A positive outlook can go a long way to helping kids adjust to the changes. Last year, a parent in Illinois decided to show her enthusiasm by starting a campaign to feature special needs kids in back to school ads. A novel idea and something that could positively impact the way special needs kids feel about school.

The good news is that parents don’t have to go to great lengths to get their kids fired up about learning. A fun idea is for parents to create a back to school learning station with their child. This can be as simple or as involved as you like. The point is for the parent to actively involve the child, making them feel included. Parents looking for some inspiration should take a look at this impressive learning station. Another way to foster a learning environment is to create a space in the house for doing homework. Kids tend to feel more secure and thrive when there’s structure.

4. **Use this as an opportunity to bond**
Children with special needs increasingly feel isolated and alone. By spending quality time with your child, you can help reduce the sense of loneliness and isolation felt. There are many ways you can bond with your child. This depends on the individual child’s needs and interests and could include anything from playing games to storytelling.

5. **Let your child develop social skills**
For many special needs parents, the idea of sending their child to school is terrifying. Others are so overprotective that it can be stifling for a child. Sending a special needs child to school can be an immensely positive experience. It’s an opportunity for a child to interact with others and to develop social skills.
**Join us for Free Webinars on topics related to Special Education!**

**Introduction to Special Education** - Do you suspect your child could benefit from special education and related services? or, Is your child newly evaluated? If so, this training is perfect for you. This intro to special education will give you a strong foundation to build future knowledge. You will learn the very basics through the philosophy of special education, the laws, evaluation process, and ultimately an IEP.

**Date:** Wednesday, July 10, 2019  
**Time:** 9:00 p.m. - 10:00 p.m.  
**Audience:** Parents, Caregivers, and Professionals of School-Aged Children/Students.

**Registration link:** [https://tinyurl.com/yyscmxog](https://tinyurl.com/yyscmxog)

**IEP Tips & Pointers** - This webinar features tried and true tips on how to positively advocate for your children, strengthen the relationships between parents and service agencies, and help create the appropriate IEP program. This webinar is perfect for families looking for ways to make the IEP meeting a more positive experience for everyone involved.

**Date:** Tuesday, July 23, 2019  
**Time:** 7:00 p.m. - 8:00 p.m.  
**Audience:** Parents, Caregivers, and Professionals of School-Aged Children/Students.

**Registration link:** [https://tinyurl.com/y3v9tupa](https://tinyurl.com/y3v9tupa)

**IEP Tips & Pointers** - This webinar features tried and true tips on how to positively advocate for your children, strengthen the relationships between parents and service agencies, and help create the appropriate IEP program. This webinar is perfect for families looking for ways to make the IEP meeting a more positive experience for everyone involved.

**Date:** Monday, August 5, 2019  
**Time:** 9:00 p.m. - 10:00 p.m.  
**Audience:** Parents, Caregivers, and Professionals of School-Aged Children/Students.

**Registration link:** [https://tinyurl.com/y2qhtofo](https://tinyurl.com/y2qhtofo)

**Basic Rights in Special Education** - Whether you are new to special education or involved for a while, this workshop is for you. This presentation provides families with an introduction to their rights and responsibilities as parents of children with special needs under the individuals with disabilities Education Act (IDEA).

**Date:** Tuesday, August 6, 2019  
**Time:** 10:00 a.m. - 11:00 a.m.  
**Audience:** Parents, Caregivers, and Professionals of School-Aged Children/Students.

**Registration link:** [https://tinyurl.com/y5qb3vm7](https://tinyurl.com/y5qb3vm7)

**Anatomy of an IEP** - Like a biology student, this presentation will dissect the parts of the IEP document and examine their functions individually, learning their meanings and application. It will provide constructive and practical tips to help create an IEP that supports all of the student’s needs. We will explore the parent’s role in the IEP process and learn the basics of their child’s right to special education services, the process of developing special education plans, and the parent’s role.

**Date:** Saturday, August 24, 2019  
**Time:** 10:00 a.m. - 11:00 a.m.  
**Audience:** Parents, Caregivers, and Professionals of School-Aged Children/Students.

**Registration link:** [https://tinyurl.com/y5lwssl2](https://tinyurl.com/y5lwssl2)
Dear (Congressman, Lawmakers, Companies, Influencers)

I’m writing this letter in regards to handicap accessible bathrooms. While families of loved ones appreciate the bigger stalls, it is just not enough. My daughter Hannah is 7 years old and has a rare disease called Rett Syndrome. She requires a wheelchair and has to, unfortunately, use diapers. When we are out in the community, traveling to doctors, vacationing, at sporting events, shopping, etc., it is a huge issue when it comes to changing her diaper. Baby changing tables are too small so our only option is to change her on a public restroom floor or on our vehicle wheelchair ramp. We change her outside on the ramp in the cold, snow, heat and rain. One time my husband was by himself with her at the New Orleans Zoo and had to change our daughter on the bathroom floor in the men’s restroom. Imagine the loved ones that are having to change an adult child, parent, or patient. Lifting them out of their chair, onto the floor or ramp is virtually impossible, therefore requiring them to stay at home and not participate in their community, or worse, sitting in a soiled diaper for an extended period of time. My daughter, like many others that must wear diapers beyond infancy, has a very difficult life. We wake up every single day another obstacle before us. We are battling her disease, insurance, doctor bills, seizures, inclusion, and of course…a place to take care of a basic need, etc. I could go on...

My daughter is the most amazing person I know. Her strength, willpower, and joy (despite her situation) has completely changed my life. She deserves better. She deserves the best. Changing her outside or on a public restroom floor is degrading and inhumane. She has rights and deserves a proper place to take care of her needs, a need that we all have. Imagine if this were your child, grandchild, mom, sister, or any loved one. As a (company, congressman, lawmaker) you have the resources to make a difference.

I don’t want to complain about an issue and not offer some solutions. I have researched options that would help alleviate this difficult situation for many. I would also suggest focus groups or reaching out to your community for suggestions that would benefit their families. This is an issue that should have been addressed decades ago. Pampers has taken a stand for baby changing tables in Men’s restrooms while New York and California have passed laws (BABIES Act) requiring “safe and compliant” changing tables. Where are these laws for my daughter who requires handicap accessibility? If this is resolved you will be changing so many lives and set yourselves apart as an example for other companies and lawmakers. Please take this matter to heart and set the standard for our nation!

Best regards,

Denay Hooks (mother of Hannah Hooks)
Emergency Preparedness For Children With Special Needs

Follow these steps to help you prepare for an emergency or disaster with your child’s special health care needs or disability in mind.

Create a Plan

The first step to creating an emergency plan is to sit down and talk with your family about different types of emergencies, how to prepare for them, and brainstorm ideas of how to care for your child with special needs during an emergency.

1. Assess your situation
Reflect and plan for your child’s needs if there was:
- No water, electricity, telephone, heat, air conditioning, or refrigeration
- No local access to prescription refills or health products
- Separation from family members
- Inability to leave your home or need for evacuation
- Limited health care access and emergency rescue services
- A lack of transportation

2. Start Planning
- Plan for backup sources of heat, refrigeration, and electricity.
- You can use a Red Cross shelter for storing medicine, charging equipment and getting meals. You do not have to be staying in a shelter to use its resources.
- If your child depends on dialysis or other life sustaining treatment, know the location of more than one facility: find out the facility’s plans for emergencies and how your child will get treatment, medications, etc. Get their emergency contact numbers.
- Create and practice an escape plan for your home.
- Be sure there are clear exit paths for a child who uses mobility devices or has vision loss.
- Talk to your local police and fire departments to see if they have emergency services or plans for people with special needs.

Smart 911 is a free service that allows families to create a safety profile for their household that includes any information they want 9-1-1 to have in the event of an emergency.

- Obtain a medical alert and/or identification bracelet for your child. Some organizations sell decals that can be put on the home or car to alert responders that there is a child with special needs (see example).
- Ask for the emergency plan at your child’s school or child care. Plan with them how your child will get the care they need in an emergency.

3. Create a support network
Create a network of family, neighbors or friends that can help you and your child.
- Tell them about your child’s special needs and share your emergency plan and where your emergency supplies are stored.
- Give a trusted member of your network a key to your home.
- Agree upon a system with your network to signal for help if phones, electricity and internet/networks are not working.
• Show others how to handle your child’s wheelchair or other equipment.
• Download our ‘Emergency Preparedness for Children with Special Needs’ tips (English, Spanish).

Pack an Emergency Supply Kit
In addition to supplies needed for a general disaster kit, you may need to add several things to the kit for your child with special needs.

General Information and Supplies:
• A current copy of your child’s Care Plan, including the In Case of Emergency Form.
• Current medical information and records stored on a CD, flash drive, or phone app (keep one paper copy in a waterproof bag).
• Batteries for hearing aids and communication devices.
• Special dietary foods and supplies.
• Items that calm or entertain your child.
• Identification to be carried by each child in case your family gets separated.

Power Supplies:
• A generator for back up power support (due to deadly fumes, never use a generator indoors).
• An AC adaptor for your car to charge small electrical equipment such as a nebulizer.
• Battery powered versions of medical equipment your child uses.
• Manual wheelchair or other non-electric equipment.
• Backup chargers a cell phones. This include a hand-cranked USB cell phone emergency charger, a solar charger, or a battery pack. Some weather radios have a built in hand crank charger.
• Backup chargers for a laptop or tablet could include a 12V USB adapter that plugs into a car, an inverter, or a battery jump pack with a USB port.

Medical Supplies and Medications:
• Talk with your child’s doctor about how to get an emergency supply of medicines. If your child takes medicine given by a clinic or hospital, talk with them about how to plan for a stoppage due to a disaster.
• Ask your pharmacist how long the medicine can last and storage needs of the medicines.
• Keep a two-week supply of medical care items such as needles, nasal cannulas, bandages, etc.
• Keep a cooler and chemical ice packs for storing medications that must be kept cold.
• Keep prescription information in your wallet, survival kit and car that includes the name, location and phone number of an out of town pharmacy.

Other Helpful Tips:
• Pack smaller “to go” kits for use in an evacuation. Store them in multiple places such as your car, at work and at school.
• Update supplies yearly, replace water every six months, and update emergency contact and medical forms as needed.
• If you can’t contact your doctor or pharmacy in a disaster, ask for help from emergency responders or staff at emergency shelters or service centers. You can get help in getting medication from a Red Cross shelter or by dialing 211 for the Washington State Information Network.

Emergency Preparedness Resource List

Special Needs Information
• For children with special nutritional needs: Disaster Preparedness Checklist
• Keeping Children and Youth with Special Health Care Needs Safe During Emergencies and Disasters from Family Voices.
• Emergency Preparedness for Individuals with Disabilities or Access and Functional Needs from Ready.gov
• For public health professional and health providers—training courses on Emergency Preparedness and Response for Vulnerable Populations from PERLC/Northwest Center for Public Health Practice.

General Emergency Preparedness Information
• American Red Cross
  • [https://cshcn.org/resources-contacts/emergency-preparedness-for-children-with-special-needs/](https://cshcn.org/resources-contacts/emergency-preparedness-for-children-with-special-needs/)
What is Children’s Special Health Services?

Children’s Special Health Services (CSHS) is a program for children in Louisiana with special health care needs. A child with special needs is:

1. a child with a health problem that affects how the child grows, moves, and acts, **AND**
2. a child who needs more health services than most other children.

CSHS gives a child with special needs health care that is sensitive to his or her family and culture. This will help the child live a happy and more independent life.

What help does CSHS offer?

- **Doctors and other health care workers** who provide services for children with special needs
- **Care coordination** to make sure a child gets all the services he or she needs
- **Hospital care**
- **Tests:** X-ray, lab, EKG (to look at heart movement), and more
- **Therapy** that helps a child (1) move better, (2) speak better, and (3) build
- **Medicine** that is ordered by CSHS doctors
- **Nutrition** and special diets
- **Equipment:** wheelchairs, braces, and more
- **Parent and family** support
- Help finding **home care** services
- Help working with **schools and community** groups and offices
- Help shifting to **adult life and care**

Who can get help from CSHS?

- A child can get help from CSHS if he or she:
  - lives in Louisiana
  - is less than 21 years old
  - has a health problem that CSHS covers
  - has Medicaid **OR** meets CSHS income rules

How do I apply?

To get help from CSHS, a parent can apply at a local parish health unit or one of the nine CSHS offices. A referral from a doctor, nurse practitioner, or audiologist is needed.

**Region 8**
Children Special Health Services
**Venice Page, Parent Liaison**
1650 Desiard St. Monroe, LA. 71201
318.361.7282
Parishes: Caldwell, E. Carroll, Franklin, Jackson, Lincoln, Madison, Morehouse, Ouachita, Richland, Tensas, Union, W. Carroll
Individuals with developmental disabilities, their families and other advocates tirelessly advocated before and during the 2019 Legislative Session for issues and funding that will improve the quality of life of Louisiana’s citizens with developmental disabilities and their families. In many ways, this session was a huge success: funding was appropriated to restore home and community-based provider rates to 2008 levels, a new program to serve “the TEFRA population” is on the horizon for 2020 (pending CMS approval) and two of the human services districts/authorities with the lowest state funding per capita received additional funds to serve their regions.

While advocates celebrated these significant gains, there were issues not addressed by the legislature that disappointed many families. A push to ensure cameras were installed in special education self-contained classrooms upon request by a parent stalled after passing the House and the Senate Education committee. Additional funding for the State Personal Assistance Services program (SPAS) to serve all individuals on the program’s waiting list was also left out of the budget.

As we reflect on this past session, one thing is clear – LaCAN advocates in their recognizable yellow shirts have a powerful collective voice with an effective message that resonates with legislators. Advocacy truly does work!

**Results for Home and Community-Based Supports**

On April 2, 2019, the Louisiana Department of Health (LDH) announced rates for the four home and community-based waivers and support coordination for people with developmental disabilities would be restored to 2008 levels for the remainder of Fiscal Year (FY) 2019. The supplemental appropriations bill for FY19, [HB362](#), went a step further and retroactively restored rates to January 2019. Advocates joined providers to successfully ensure legislators added this rate restoration to the main state budget bill for FY20, [House Bill (HB) 105](#), and included rates for the Office of Aging and Adult Services Waivers, Medicaid Long-Term Personal Care Services, and EPSDT Personal Care Services. The $38.8 million in state funds appropriated for the rate restoration also included a rebase of rates for Intermediate Care Facilities for People with Developmental Disabilities.

The impact of the rate restoration cannot be overstated. Louisiana is experiencing a severe shortage of Direct Support Professionals due to the low provider rates and accompanying low wages. Testimony throughout the session provided examples of individuals’ inability to find and keep staff and providers’ inability to continue to provide quality services. The Community Provider Association, Supported Living Network, and Arc of Louisiana did an excellent job educating legislators on the issue. Individuals with disabilities and families made the case with their compelling personal stories. And LDH leadership clearly communicated that rate
restoration was a priority! It was a collaborative effort that worked! While the 2008 rates do not account for inflation, this is a HUGE first step in the right direction of ensuring quality services for individuals with disabilities and their families.

In addition to this rate package, HB105 includes:

- Language directing LDH to begin a program to serve the TEFRA population beginning on or before June 1, 2020, pending CMS (federal Medicaid agency) approval; (more details below)
- $1 million in additional state funds for Northwest LA Human Services District; and
- $1 million in additional state funds for Florida Parishes Human Services Authority.

HB199 by Representative Dodie Horton sailed through both chambers of the legislature unopposed with 48 representatives and 24 senators signing on as co-authors. Known as the TEFRA bill, HB199 requires LDH, pending CMS approval, to begin a program to provide health care services via the state’s Medicaid program to children in the TEFRA population no later than June 1, 2020. The bill was amended several times throughout the process, mainly to avoid a fiscal impact in the FY20 budget and to control the fiscal impact in future years.

The creation of this program in statute is also a huge accomplishment. The Council and advocates have advocated for the implementation of TEFRA numerous times over the past 28 years, and while support, and even funding, were provided by the legislature in the past, both of these were withdrawn at the eleventh hour. HB199 finally puts relief within reach of families desperate for Medicaid coverage for their children with developmental disabilities. The final version of HB199 gives LDH the leeway to determine the number of children served and to define the population group. Ongoing advocacy by the Council and parents will be needed to ensure all children with developmental disabilities are included in the plan submitted to CMS.

Results for Education
Parents passionately testified and advocated throughout session for protections for their children who are served in special education self-contained classrooms. HB283 by Representative Mark Wright would have required cameras be placed in these classrooms upon a parent’s request. It is well documented that students with disabilities, particularly students who are non-verbal, are at a greater risk of abuse and do not have the communication skills to self-report this abuse. Not only would video and audio surveillance increase student safety, it would also protect educators from false accusations and promote improved training to address student challenging behaviors. Unfortunately, HB283 did not pass the legislature.

However, parents are very happy with the passage of Act 117 (HB320) by Representative Scott Simon. Act 117 amends current law to include Applied Behavior Analysis (ABA) providers in the definition of a behavioral health service provider in order to allow these providers access to students during school hours upon request of the parents. It also requires each public school governing authority to make public its policies regarding behavioral health services being provided to students while at school. Senate Bill (SB) 78 by Senator Danny Martiny brought a companion bill to Act 117 that did not pass.

Other Bills of Interest
Act 57 (HB143) by Representative Malinda White, also known as Evie’s Law, prohibits discrimination against potential organ transplant recipients based on disability.
HR160 by Representative Joseph Bouie requires the collection and reporting of certain information relative to school safety and discipline including numbers of school resource officers and student suspensions, expulsions, removals to alternative settings, referrals to law enforcement, and school-related arrests. This bill is currently awaiting executive approval by the Governor.

HB390 by Representative Malinda White requires LDH to collect and maintain reliable data regarding disability service provider rates and determine the sufficiency of each rate. It also requires LDH to submit an annual report to various legislative committees that includes any changes to the Medicaid rate methodology for disability services, current Medicaid rates for services, information on past and upcoming rebasing of intermediate care facilities for people with developmental disabilities, funding needed to adjust rates annually based on inflation, and any proposed changes to the current rate methodology. This bill is currently awaiting executive approval by the Governor.

HB507 by Representative Neil Abramson requires a fee be assessed on sales of therapeutic marijuana with the proceeds being deposited into the Community and Family Support System Fund. It also stipulates that no less than 50% of the proceeds be used toward EarlySteps funding. This bill is currently awaiting executive approval by the Governor.

SB120 by Senator John Milkovich threatened to allow any school personnel to remove students from a school campus, allow the use of force and physical restraint, and involve law enforcement in the removal of students from campus in response to student behavioral challenges. This bill failed to make it out of committee.

SB137 by Senator Wesley Bishop sought to rearrange all the laws related to student discipline and behavior to group similar items together. The goal was to improve readability based on a recommendation by the Advisory Council on Student Behavior and Discipline (ACSBD) to rearrange one section of the law (i.e., R.S. 17:416). However, after the ACSBD’s Legislative Workgroup reviewed a cross reference of SB137 to existing laws, it was realized SB137 contained some significant language changes to existing statute. Some of the changes identified would be problematic for schools, and due to the massive amount of cross-references, the group could not be certain all differences to law in SB137 were identified. Senator Bishop did not move this bill forward.

SB151 by Senator Jay Luneau authorizes the transfer of the Louisiana Special Education Center from the Special School District to LDH and renames the center the Central Louisiana Supports and Services Center. This bill is currently awaiting executive approval by the Governor.

SB158 by Senator Jack Donahue requires each local public school superintendent and the administrative head of each charter school to establish a special education advisory council to provide advice and feedback regarding special education policies, procedures, and resources and engage in community outreach. It also requires 50% of the advisory council membership be made up of parents of students with an exceptionality other than gifted and talented. This bill is currently awaiting executive approval by the Governor.

SB173 by Senator Fred Mills would only take effect should the Patient Protection and Affordable Care Act (ACA) be ruled unconstitutional. This law would provide standards for open enrollment, rate setting, and coverage for dependent children who are under the age of 26. It also prohibits preexisting condition exclusions and annual and lifetime limits. This bill is
Families Helping Families  
Lending Library

Families Helping Families has a lending library, books, dvds and more are here, free of charge for families and professionals to check out. You are welcome to come and browse our library during our office hours, Monday through Friday, 8 am to 4 pm.

Adult Opportunity Book Clubs

The Adult Opportunity Book Clubs are for adults with developmental disabilities regardless of their reading ability. Participants meet weekly for an hour at Joe Muggs Coffee Shop inside Books a Million and discuss a chapter of the book the group is currently reading. We currently have four groups that are meeting and we are supplying support to a group.

Friday Focus

Once a month, adults who are out of high school are invited to participate in an activity sponsored by FHF. The group get together one a month to have fun, meet new people, and participate in activities, and community activities. Some activities include bingo, bowling, kite flying, Fall Festival, and Health Fair holiday celebration plus much more. If you are interested in attending one of our events, just call 318-361-0487 and ask to put your name on the mailing list. Can't wait to see you!
Join us for this month’s

**Lunch & Learn Series**

With special guest Sharon Hennessey, Executive Director of

![People First of Louisiana](https://example.com)

**People First of Louisiana:**
- Is a self advocacy group run by people with disabilities, for people with disabilities.
- Where people learn to speak up for themselves about decisions they make.
- Members can connect with others in their community, across the nation and around the world.
- Members learn about their rights and responsibilities as citizens of the United States of America.

July 10, 2019
11:00am-1:00pm
Families Helping Families
5200 Northeast Road, Monroe, LA 71203
Call 318-361-0487 or email [sguidry@fhfnela.org](mailto:sguidry@fhfnela.org) to RSVP

**Learn how YOU can be YOUR best ADVOCATE!!!**
Save the date!  Save the date!

Regional Advisory Committee Meeting

Tuesday, July 23rd at 1:30 pm

![Summer Image]

Please make every effort to attend!

Families Helping Families Building

5200 Northeast Rd., Monroe, LA 71203

Please call Northeast Delta Human Services Authority (NEDHSA) at 362-3396 if you have questions or will be unable to attend.
Thursday July 25th 9 AM – 11 AM

Guest Speaker: Angie Snuggs

Richland Parish Special Ed Supervisor-
Mrs. Snuggs brings more than 28 years of direct educational support to students
as a teacher, principal, and special education supervisor.

RSVP: 318-361-0487

WHAT YOU WILL LEARN:

• We will provide a better understanding of a parent’s role and responsibilities from an educator’s point of view.
• Train and encourage parents to communicate with their child’s teachers.

*Lakeisha Bosworth and Angela Greer from the Ouachita Parish Library will provide a constellation activity for any children who attend.
Please help bring this event to the Monroe area for fun and funding. Vehicles are needed to be loaned for the day and Event Sponsors are being sought. Sponsorships range from $100.00 up to $2500.00 with in Touch A Truck part to media recognition given to your organization for helping.

If you are interested in assisting this outstanding organization, please contact Families Helping Families’ executive director, Stacey Guidry at 318-361-0487 or sguidry@fhfnela.org.

Contact Families Helping Families for a registration form and Sponsorship form 318.361.0487.
The 2019 Twin Cities Mayor's Committee on Disabilities Awards Banquet

July 16, 2019
6:00 pm

West Monroe Convention Center
901 Ridge Ave
West Monroe, LA 71291

Banquet Tickets $30
Corporate Table $200
8 per table

To get your ticket go to
www.tcmcd.com

Families Helping Families of Northeast Louisiana, Inc.
5200 Northeast Road
Monroe, LA  71203