



Families Helping Families

Region 7



Serving: Bienville, Bossier, Caddo, Claiborne, DeSoto, Natchitoches, Red River, Sabine, and Webster

In Their Own Words: When Angels Walk the Earth By Maggie Dunne

When I first learned that my mom was pregnant with a baby girl, I was ecstatic! More than anything, I wanted to be a “perfect” big sister. I wanted my sister to ask me all of her questions and tell me all of her secrets. The day Deirdre came home from the hospital I asked, “Mommy, when is Deirdre going to talk?” and my mom replied, “Soon honey, you have to be patient.” I counted the hours and minutes with building anticipation for the moment when I would finally be able to engage in a conversation with my little sister. At six years old, I was ready to assume my new role and responsibility as her mentor in life.

Sure enough, as time passed, Deirdre started to talk; however, after progressing “normally” for almost three years, Deirdre inexplicably regressed. In addition to losing her ability to speak, she lost many of her motor functions and cognitive skills over the following year. I remember asking, “Mommy, why isn’t Deirdre talking?”, but this time my mother replied, “Maggie, I don’t know.” At nine years old, I knew that my family’s life would never be the same.

Words cannot adequately describe the devastation that gripped my family when Deirdre was diagnosed with autism. While the little sister I once knew was now very different, it was clear that the situation was far more frustrating and devastating for Deirdre than it was for any of us who love her.

Deirdre’s world presents her with constant challenges, and she struggles to navigate even the simplest aspects of daily life. At first I thought that Deirdre would never be able to eat on her own, behave well in public, communicate with us, or even sleep through the night. However, as time passed, Deirdre’s strength and perseverance put all my doubts to shame. No matter what struggle she faces, no matter how hard she tries to perform a task or to communicate, no matter how frustrated she feels, Deirdre smiles and perseveres, and her positive attitude remains a constant. At eighteen years old, I realize that although Deirdre will never be able to tell me her secrets or ask me about boys, she has given me far greater gifts.

Deirdre’s strength has shown me the power of optimism and hope. When I began figure skating at the age of twelve, my coaches told me that I was “too old” to expect to learn double jumps. However, I never doubted my ability to reach my goals. Having mastered singles and doubles, I am now working on triple jumps. Similarly, when my peers doubted the value of the coat and book drive I organized for children of the Lakota Nation, and my ability to subsequently get thousands of items out to the Pine Ridge reservation in South Dakota, I thought of Deirdre, who despite her prognosis never gives up and continues to fight for her voice. This, in turn, empowered me to fight for the children of the Lakota Nation and resulted in a greater success than I ever thought possible. Being witness to Deirdre’s ability to remain positive and to tackle challenges has inspired me to face every challenge with the same strength and courage that I see every day in Deirdre’s eyes.

Finally, living with someone who is judged so often has taught me the importance of suspending judgment and recognizing that everyone has something to contribute to the world. I have experienced the pain caused by irrational judgment. Whether this is in the form of an angry sneer at a restaurant or a piercing stare at the mall, when strangers greet Deirdre in public with judgmental expressions, I hurt for her. The depth of Deirdre’s character is a testament to the need to look beyond physical and social differences.

Every year, through Midnight Run, I help distribute food, clothing, and everyday essentials to homeless men and women on the streets of New York City. While the recipients are in need of material goods, they are also in search of some positive human interaction. Because I have experienced the pain associated with judgment, I am able to look past the unfortunate circumstances of this ostracized population and make the effort to connect with them on a personal level through conversation. While some people just want to make small talk, others will ask me about what I am learning in school and want to reminisce about their own childhoods and the circumstances that led them to be on the streets. Having an open mind and an open heart has enabled me to touch the lives of others, while feeling deeply touched in return.

Who?	What?	When?	Where?
A family directed resource center for all individuals with disabilities and their families	Providing information, referral, and support through a network of services and assistance throughout Region	8:00 am – 5:00 pm Monday – Friday Drop-ins are always welcome!	2620 Centenary Boulevard Building 2, Suite 250 Shreveport, LA 71104 318.226.4541 877.226.4541 fhfregion7@bellsouth.net www.fhfregion7.com

IDEA 2004

The Individuals with Disabilities Education Act (IDEA) is the federal law that secures special education services for children with disabilities from the time they are born until they graduate from high school. The law was reauthorized by Congress in 2004, prompting a series of changes in the way special education services are implemented. These changes are continuing today and they affect the delivery of special education and related services in your state. The IDEA Partnership can help you keep up with the changes and possibly influence future decisions.

The law itself is detailed and complex, but here are some key components:

- History
- Purpose
- Components
- Helpful information about aspects of the law
- The law
- More information

History

IDEA has undergone several changes since it began as the Education for All Handicapped Children Act (EHA), or Public Law 94-142, in 1975. This law originated as a way to insure that students with disabilities receive an appropriate public education.

IDEA has been updated about every five years since its beginnings, the latest of which is the 2004 reauthorization. The reason for this consistent updating is to give us a chance to see how the law plays out in practice, and what we need to do to make it more clear, efficient or effective. In 1986, for example, the infant and toddler component was added, and in 1990, transition planning became a requirement.

Several ideas have become part of the special education vocabulary because of this law, including FAPE (free appropriate public education), IEP (individualized education program) and LRE (least restrictive environment). These concepts have been built into the special education system to insure equal access to education for all students.

In 2006, another change was made when final regulations were released for IDEA 2004. For years, schools were required to wait until a child fell considerably behind grade level before being eligible for special education services. Today, with the release of the final regulations of IDEA 2004, school districts are no longer required to follow this 'discrepancy model,' but are allowed to find other ways to determine when a child needs extra help. This is being implemented throughout the country through a process called Response to Intervention.

Purpose

The reauthorization of IDEA 2004 (Section 601(d)) states that the purpose of the law is:

- (1A) to ensure that all children with disabilities have available to them a free appropriate public education that emphasizes special education and related services designed to meet their unique needs and prepare them for further education, employment and independent living;
- (1B) to ensure that the rights of children with disabilities and parents of such children are protected;
- (1C) to assist States, localities, educational service agencies, and Federal agencies to provide for the education of all children with disabilities;
- (2) to assist States in the implementation of a statewide, comprehensive, coordinated, multidisciplinary, interagency system of early intervention services for infants and toddlers with disabilities and their families;
- (3) to ensure that educators and parents have the necessary tools to improve educational results for children with disabilities by supporting system improvement activities; coordinated research and personnel preparation; coordinated technical assistance, dissemination, and support; and technology development and media services; and
- (4) to assess and ensure the effectiveness of efforts to educate children with disabilities.

Note: The phrase "further education" is new in 2004, as is the increased emphasis on effective transition services to promote successful post-school employment or education.

Components

IDEA is divided into four sections, Parts A - D.

Part A defines the terms used in the law.

"Specific learning disability" is defined as follows:

- **The term "specific learning disability" means** a disorder in one or more of the basic psychological processes involved in understanding or in using language, spoken or written, which disorder may manifest itself in the imperfect ability to listen, think, speak, read, write, spell, or do mathematical calculations.
- **Disorders included.** Such term includes such conditions as perceptual disabilities, brain injury, minimal brain dysfunction, dyslexia, and developmental aphasia.
- **Disorders not included.** Such term does not include a learning problem that is primarily the result of visual, hearing, or motor disabilities, of mental retardation, of emotional disturbance, or of environmental, cultural, or economic disadvantage.

Part B gives money to states to provide services for eligible children and youth with disabilities, including the rules and regulations that states and school systems must follow to receive funds from the federal government.

This section outlines:

- evaluating children and determining eligibility for services
- notifying and involving parents
- working with parents to write IEPs
- providing services
- resolving conflicts between parents and the school system
- providing accessible text to students under NIMAS
- and more

Part C is the Early Intervention Program for Infants and Toddlers with Disabilities. Services that may be included in this program are family training, counseling, home visits, speech-language services, occupational therapy and physical therapy.

Part D helps state education departments and other agencies improve how they work with children and youth with disabilities.



Tips for Improving Communication Skills for Caregivers

Effective communications is the most important skill for family caregivers, especially those of us who are working caregivers. Communication with the medical professionals; elder care providers such as Meals on Wheels and home health staff; and with siblings is essential for safe and effective care giving.

The most important communication that a caregiver may most need to improve, however, is communication with the care receiver! Aging relatives or older adults are independent and have their own ideas and opinions about their lives and care worthy of our respect. Most people would agree that usually the biggest problem in relationships involve communication.



Listed below are tips for caregivers to improve communication to avoid problems and improve the overall care of a parent, spouse or other care receiver.

1. **Breathe.** Take a couple of deep breaths before you start a conversation. Breathing is a good way to relax and it gives you time to put thoughts in proper order. If the conversation becomes emotional or difficult, stop and take another few deep breaths to help you calm down and focus.
2. **Ask questions.** Find out what is really going on. Are you assuming some things about what the other person is saying because you think you know everything that is going on?
3. **Really listen.** As someone once said: Remember, we have two ears and one mouth. Listen to what the person says and check out what the person is hearing you say. For example, Do you agree that we might want to call the nurse and talk to her about this problem with your medication? Listen to silence. Silence allows someone to think about what is being discussed or about a response.
4. **Use body language to improve communication** (non-verbal cues in how you use eye contact, gestures, and your distance from the person). Look the person in the eye. Lean into the person or put a hand on the persons arm or shoulder but remember that not everyone likes to be touched.
5. **Slow down.** Take your time. Avoid trying to talk about and do everything at once. Communication at an even pace allows everyone to think through the conversation and how to respond.
6. **Listen to what the person is saying and how they are behaving.** Do the words and the behavior match? Could the person be talking about something very different than what they really want but she does not know how to say it or ask for something? Be aware that fear may make someone hesitate to say what is really going on. Most care receivers fear admitting to certain problems and concerns that may lead to a further loss of independence

7. **Speak directly to the elder or person you're communicating with.** It may be easy for caregivers to multi-task as they prepare meals, do laundry, take someone to the grocery store, or accompany a parent to a doctor appointment. Set aside time to have one on one conversation. This may save time in the long run because misunderstandings can be avoided. If the care receiver feels heard and understood she may talk about something that is a concern but felt that you were rushed. Identifying concerns and problem- solving can avoid problems later.
8. **Speak distinctly and clearly but not louder.** Some older adults do not like to admit that they may not hear and understand conversations around them. The higher pitch of many women's voices may be a problem for some older adults so women may need to consciously lower their voice.
9. **Do not argue.** Listen to concerns and try to understand the other persons experience and opinions. Remember that it is still his or her life and care. Focus on meeting unmet needs and not conflict.
10. **Try to laugh, when appropriate and use humor when appropriate.** Humor can help ease tension. Most caregivers and care receivers know each other well enough to find humor in the situation.

What is Independent Living?

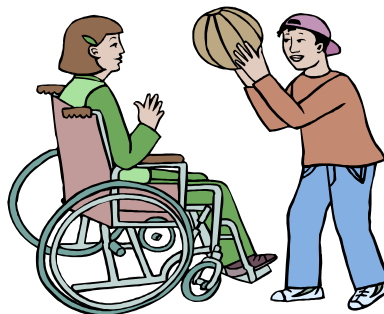
Independent Living, as seen by its advocates, is a philosophy, a way of looking at disability and society, and a worldwide movement of people with disabilities who proclaim to work for self-determination, self-respect and equal opportunities.

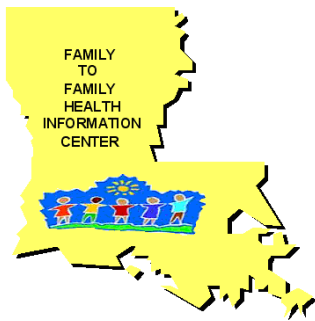
Independent Living means being in control of your own life, taking responsibility for your actions, taking risks, and either failing or succeeding on your own terms. It means participating in community life and pursuing activities based entirely upon self-determined interests and preferences. To support these goals, Independent Living Centers help individuals of all ages with all types of disability to obtain whatever services they need to preserve their right to choose and to fully and equally participate in society.

In the Independent Living philosophy, disabled people are primarily seen as citizens and only secondarily as consumers of healthcare, rehabilitation or social services. As citizens in democratic societies, the Independent Living Movement claims, persons with disabilities have the same right to participation, to the same range of options, degree of freedom, control and self-determination in every day life and life projects that other citizens take for granted. Thus, Independent Living advocates demand the removal of infrastructural, institutional and attitudinal barriers and the adoption of the Universal Design principle.

According to the Independent Living Movement, with peer support, everyone - including persons with extensive developmental disabilities - can learn to take more initiative and control over their lives. For example, peer support is used in Independent Living Skills classes where people living with their families or in institutions learn how to run their everyday lives in preparation for living by themselves.

Currently some two million Americans with disabilities are confined in nursing homes, care facilities, and other institutions not because that is what they want or need, but because that's what the government will pay for.





The LA Family to Family Health Information Center recognizes National Epilepsy Awareness Month in November with information on seizure first aid for all individuals touched by someone with epilepsy. If you or your child has epilepsy or a seizure disorder, print this page for seizure first aid and facts and ask family, friends and teachers to read it and become more aware.

For more resources and information about epilepsy or seizure disorders, please contact the Louisiana Family to Family Health Information Center at 1-800-331-5570.



Seizure First Aid

Above anything else, if you see a person having a seizure you should remain calm. Getting excited will not help you, nor will it help the person having a seizure. Otherwise, there are only a few things to remember:

1. Check for medical identification, such as a necklace or bracelet. If none is present, and no one can affirm that the person has a seizure disorder, call for medical attention.
2. For tonic clonic seizures: loosen constrictive clothing such as neckties or scarves, and cushion the person's head with a pillow, blanket, jacket, towel, or any other soft object. Turn the person on one side to allow for excessive salivation to drain sufficiently, and for the tongue to remain clear of the person's airway. (Note: a person **CANNOT** swallow his/her tongue; please do **NOT** put anything in the person's mouth). Time the seizure, and if the seizure goes beyond five minutes, consciousness does not return soon afterward, or if further seizures follow, call for medical attention. The person may need to rest after the seizure. Do not allow food or drink until full consciousness has returned.
3. For complex partial seizures: do not yell or shout at the person having the seizure, nor should you expect verbal commands to be obeyed. Stay with the person, removing harmful object out of the way, gently guiding him/her away from hazards if the person becomes ambulatory. Do not restrain; the person may flail or lash out if you are perceived as a threat. Provide reassurance and support after the seizure.
4. If the person is pregnant, has diabetes, has the seizure in water, or has obviously sustained an injury, call for medical attention at once.

DID YOU KNOW THAT:

- Most seizures are NOT medical emergencies
- People may NOT be aware they are having a seizure and may not remember what happened.
- Epilepsy is NOT contagious.
- Epilepsy is NOT a form of mental illness
- Epilepsy is NOT a form of mental retardation
- People almost never die or have brain damage during a seizure

- A person CAN NOT swallow his/her tongue during a seizure.
- Epilepsy can develop at ANY age
- 20% of cases develop before the age of five
- 50% of cases develop before the age of twenty-five
- Epilepsy currently affects about 300,000 senior citizens nationwide.
- By the age of 20, 1% of the population can be expected to develop epilepsy. By the age of 75, 3% of population can be expected to have been diagnosed with epilepsy and 10% will have experienced some type of seizure.

Common Causes

For 70% of people with epilepsy the cause is unknown. For the remaining 30% common identifiable causes include:

- Brain Trauma
- Brain lesions (e.g. tumors)
- Poisoning (lead)
- Infections of the brain (e.g. meningitis, encephalitis)
- Brain Injury at birth
- Abnormal brain development

Epilepsy Shreveport Support Group
 6:00 p.m.
 2nd Tuesday every **other** month
 Meet at Christus Schumpert, One Saint Mary Place



WELCOME



Kim Clayton – Transition Specialist

I'm excited to introduce myself as the Transition Specialist, for Families Helping Families Region 7. As the Transition Specialist, I will work with students, parents, educators and community professionals as students explore opportunities for both functional and academic achievement, training, employment, independent living and community participation. I will also serve as a family support facilitator and advocate in providing assistance with school meetings, which include and are not limited to: IEP and IAP/ 504 Accommodations, School Building Level Committee Meetings, Vocational Assessments and other related services.

As the parent of three children, two of which are transition age students that receive Special Services through Caddo Public Schools, I understand the importance of empowerment and effective advocacy for our children. My goal is to educate parents and students of their rights and responsibilities through workshops, seminars and support groups.

Please do not hesitate to contact me at 318-221-2032 (Direct Line) 318-226-4541 (Center Line) or Toll Free 877-226-4541 or email me at transitionfhf@att.net. I look forward to establishing a relationship with each of our Region 7 families as we strive for students.



Carolyn Short ECSS Family Facilitator

Hello my name is Carolyn Short. I am the Family Facilitator for ESCC (early childhood supports and services) in Desoto Parish. I am married and have two beautiful sons that we adore. My youngest son were diagnose developmental delayed at the age of one. ECSS is a program that provides services for at risk children. If you are a parent in Desoto Parish that is concern about your child behavioral, developmental stages or if you feel your child need help in a particular area and you want to have a peace of mind. ECSS is an agency that works with families of children 0-6 who are at risk for developmental delays, behavioral problem, or mental illness. If there are any question about ECSS please contact the ECSS office at (318) 872-2055 or the FHF center at (318)226-4541/1-877-226-4541.



Mary Russell – OCDD Family Facilitator

I am excited about my move to Families Helping Families Region 7. I will continue to serve the parishes of Region 7 which include Caddo, Bossier, Webster, DeSoto, Sabine, Natchitoches, Bienville, Red River, and Claiborne as the OCDD Family Facilitator.

My agency is a referral, resource and education center. I am here to offer services to families with children and adults that have developmental disabilities. Please do not hesitate to call me if I can help you or your family. I am in the office 9AM-2PM, Monday-Friday.

I know firsthand the struggles parents go through when their children have disabilities. I have three children who all have challenges. My first born son who is now 22 lives with a speech impediment. I always instilled in my children that they have abilities and not disabilities. Now my son is in the military and serving our country proudly. This past July, my daughter blessed me with my first grandchild.

I would be interested in meeting with you to discuss further our services. Please call me direct at 318-221-2031, center line 318-226-4541, 1-877-226-4541 or email me at ocdd@att.net.



Monica Stampley - Early Steps COS and her boys

I am the Early Steps Community Outreach Specialist for Region 7 which includes: Bienville, Bossier, Caddo, Claiborne, Desoto, Natchitoches, Red River, Sabine, and Webster Parishes. Early Steps is Louisiana's Early Intervention Program that serves infants and toddlers with special needs from birth to 3 years of age. I am the parent of 2 young children with disabilities, who have both received early intervention services.

My role is to assist you with understanding your rights and responsibilities within the EarlySteps system, and assist you with finding resources in the community that may benefit your family, such as support groups, trainings, workshops, etc. I am also available to answer any questions you may have about EarlySteps.

I would like to take this opportunity to invite you to our Regional Interagency Coordinating Council (RICC) meetings. EarlySteps providers and community partners, as well as EarlySteps families attend the RICC meetings. It is an opportunity to learn more about EarlySteps and other supports & resources in the community that could help strengthen your family. If you have any questions, need more information, or if you would like to be notified of any upcoming meetings and events, please contact me.



LaTEACH, Louisiana Together Educating ALL Children is a statewide grassroots advocacy organization created for the purpose of effecting systems change.

MISSION STATEMENT

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 and effective practices used appropriately for each student.

If you are concerned about the state of education in Louisiana you should join LaTEACH. You will get reliable and pertinent information on laws, proposed legislation and other issues that impact our students. Who should join students, parents, family members, educators, administrative, and any person interested in inclusive education. For more information about LaTEACH please contact the Area 4 LaTEACH Coordinator Kim Clayton at (318) 572-9753 or email her at kim.clayton@lateach.org.

Stipend Money Available!

Do you want to learn more about your child's disability? Have you heard of a new technique that might help him learn? Families Helping Families Region 7 might be able to help you get this knowledge.

There are stipend dollars available for individuals with disabilities and their families who live in the parishes of Region 7. Please apply for these funds if you would like to attend a conference, convention or other activity that will increase your knowledge.

To apply, you may call 318.227.4541/1.877.226.4541 or email: fhregion7@bellsouth.net.

Please have the following information handy when calling to ask for funding or include these details in any email:

- 1) When
- 2) Where
- 3) Registration Cost
- 4) How much you are able to contribute

This is a great opportunity to attend a state, regional or national event that otherwise might not be possible!

You are Invited.....

Families Helping Families Region 7 cordially invites you to our open house which will be held on October 29, 2009. Professionals are invited to come from 10:00am – 1:00pm and families are invited to come from 3:00pm – 6:00pm. Come out to meet our new staff and remodeled office located at 2620 Centenary Blvd Bldg 2 Ste. 250 Shreveport, La 71104. To RSVP please contact Mary Russell at 318-221-2031 or Kim Clayton at 318-221-2032. We look forward to seeing you there.

RICC Regional Interagency Coordinating Council

Chanel Jackson, Executive Director of Families Helping Families Region 7, will speak about the different programs and services the center has to offer. Come to hear updates from Early Steps Central Office and discussion of any Regional concerns. All concerns will be presented to SICCC in November.

Wednesday
October 14th, 2009
11:30 a.m.

Caddo Parish Health Unit
1035 Creswell Ave.
Shreveport, LA 71101
3rd Floor Conference Room Special Speaker:

For More Information Contact::
April Hearn, Regional Coordinator Region 7
3018 Old Minden Rd. Ste. 1211
Bossier City, LA 71112

Light Lunch will be provided by Families Helping Families Region

Become a LaCAN member

- NO DUES. NO FEES.
- You can help your family and others by joining the LaCAN Team in region 7 and participating in its advocacy efforts. Increased membership is needed for success in gaining increased funding for individual and family supports.
- Waiting lists for all components of the Community and Family Support System are very long. If you feel frustrated when needed services and supports are not available, joining LaCAN is something you can do to help change the situation.
- LaCAN members embrace the philosophy of the Community and Family Support System and are willing to write, call or visit policymakers in the state to share their families' stories.
- To join the LaCAN Team in region 7, contact the LaCAN Leader Duane Ebarb at dke1949@bellsouth.net, or call (318) 688-4830.

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Executive Director

Louisiana Developmental Disabilities Council's Mission

To ensure all individuals with disabilities benefit from supports and opportunities in their communities so they achieve quality of life in conformance with their wishes.

Through the Developmental Disabilities Assistance and Bill of Rights Act Congress funds and authorizes the Developmental Disabilities Council to conduct advocacy, capacity building and systems change activities. The Council's efforts are designed to promote the increased self-determination, independence, productivity, integration and inclusion of people with developmental disabilities in their communities.

The Louisiana Developmental Disabilities Council (DDC) is made up of people from every region of the state who are appointed by the governor to develop and implement a five year plan to address the needs of persons with developmental disabilities. Membership includes persons with developmental disabilities, parents and representatives from public and private agencies. Several members rotate off the Council each year in October and nominations for new members are always welcomed.

You may contact the DDC by calling 1.800.450.8101 or visit their website: www.laddc.org

Families Helping Families Region 7 programs and this newsletter are supported by the Louisiana Developmental Disabilities Council Louisiana State Department of Education, Office of Citizens with Development Disabilities, Office of Mental Health, and Office of Public Health

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Region 7
2620 Centenary Boulevard
Building 2, Suite 250
Shreveport, LA 71101

