



# Families Helping Families

## Region 7



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

### The Most Important Choice By Paula Scheider

I got to choose her first name - Fiona. Her father chose her middle name - Claire. I got to choose her Easter dresses, her birthday and the Winnie the Pooh motif on all of her furniture. I chose her godparents and her doctor and her first shoes. Her father chose her car seat and her bath toys and the darling little shirt that said "Oink!" with the piglet on it. We chose her Christmas ornaments and the gifts under the tree. We chose to have our Fiona. We did not choose autism. In the beginning, before I was able to get an "official" diagnosis, my choice was to comb the message boards and Google for hours. I chose to buy hundreds of dollars worth of educational toys and videos. I chose to chat online with other mothers whose children were diagnosed and I chose to cling to the ever-dimming hope that I was wrong. For weeks, I vacillated between anger and resignation, certainty and confusion, jealousy and joy. There were days where all I focused on was autism and all of the negative stories. There were nights that I did not sleep – instead I made list after list of everything Fiona would miss. Everything we, as her parents, would never experience. I mourned and I raged and I begged and I cried and I made more lists and I surfed and read and researched.

The internet is a miraculous thing. The amount of information available is overwhelming whether it's autism or auto mechanics. Want to spend hours reading tragic story after tragic story about an autistic child? I have your message board. Interested in insurance nightmares? Educational struggles? I've got another hundred message boards for you. Vaccines? Type "autism" and "vaccine" and you get almost one *million* Google hits. Or perhaps you would rather read about autism from the perspective of an adult with autism there are literally hundreds of blogs to choose from. And some are joyful and some are depressing and some are infuriating and some made me sob. I gave up a thousand times and started over a thousand and one.

Then one day, as I was wallowing in my pain and anger, a question came to mind.

*Do you want to spend time mourning the daughter you can never have or do you want to spend time loving the daughter you have been given?*

And then I made my choice. I turned off the computer and I began to dance with Fiona.

I abandoned my quest to find out "how" it happened, because frankly, I don't care.

I tore up those mental lists of everything we were cheated out of and made longer lists of our blessings and accomplishments. I dug out my sign language book from college and began working on communicating with my daughter. I made the decision to do everything I could to make Fiona's life her own, as opposed to the one I wanted for her.

I remembered that I have 3 special and unique children, not just one with autism.

I began to celebrate every small victory and accomplishment, because they mean so much more. We chose to be Fiona's mommy and daddy and not victims of autism. And now, every day, I choose to be happy.

*As a side note, it has been almost a year to the day that we were told that Fiona was severely autistic and would most likely be non-verbal. I guess no one shared that with her, since at last count, she is at close to 100 words (and Mommy is one of them!), can say her ABCs & count to 20 and can recite much of "Green Eggs And Ham" from memory. Every single day, there is another step forward what more could we ask for?*

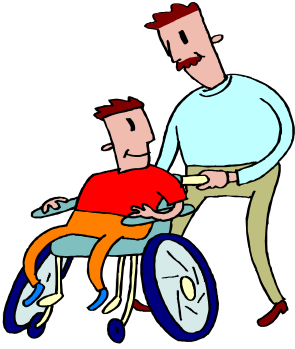
Who?	What?	When?	Where?
A family directed resource center for all individuals with disabilities and their families	Providing information, referral, and support through a network of services and assistance throughout Region 7	8:00 am – 5:00 pm Monday – Friday  Drop-ins are always welcome!	2620 Centenary Boulevard Building 2, Suite 250 Shreveport, LA 71104 318.226.4541 877.226.4541 <a href="mailto:fhfregion7@bellsouth.net">fhfregion7@bellsouth.net</a> <a href="http://www.fhfregion7.com">www.fhfregion7.com</a>

## The Importance of People First Language

According to stereotypical perceptions, they are: People who *suffer* from the *tragedy of birth defects*. *Paraplegic heroes* who *struggle* to become *normal* again. *Victims* who *fight* to overcome their *challenges*. Categorically, they are called *retarded, autistic, blind, deaf, learning disabled, etc.*, etc.

Who are they, really?

Moms and Dads. . . Sons and Daughters . . . Employees and Employers ....Friends and Neighbors . . . Students and Teachers. . . Leaders and Followers... Scientists, Doctors, Actors, Presidents, and More. **But most importantly they are people. They are people, first.**



People with disabilities constitute our nation's largest minority group. It is also the most inclusive and most diverse: genders, any sexual orientation, and all ages, religions, socioeconomic levels, and ethnicities are represented. Yet people who have been diagnosed with disabilities are all different from one another. The only thing they have in common is being on the receiving end of societal misunderstanding, prejudice, and discrimination. Furthermore, this largest minority group is the only one which *any person can become part of, at any time!* Some join at birth—others in the split second of an accident, through illness, or during the aging process. If and when it happens to *you*, will you have more in common with others who have disability diagnoses or with family, friends, and co-workers? How will you want to be described? And how will you want to be treated?

### *Using People First Language is Crucial*

People First Language puts the person before the disability, and it describes what a person *has*, not who a person *is*.

Are you "myopic" or do you wear glasses?

Are you "cancerous" or do you have cancer?

Are you "freckled" or do you have freckles?

Is a person "handicapped/disabled" or does she have a disability?

## Examples of People First Language

### **Say:**

People with disabilities.

He has a cognitive disability (diagnosis).

She has autism (or an autism diagnosis).

He has a diagnosis of Down syndrome.

She has a learning disability (diagnosis).

He has a physical disability (diagnosis).

She's of short stature/she's a little person.

He has a mental health diagnosis.

She uses a wheelchair/mobility chair.

He receives special ed services.

She has a developmental delay.

Kids without disabilities.

Communicates with her eyes/device/etc.

Customer

Congenital disability

Brain injury

Accessible parking, hotel room, etc.

She needs . . . or she uses . . .

### **Instead of:**

The handicapped or disable.

He's mentally retarded.

She's austistic.

He's Down's.

She's learning disabled.

He's quadriplegic/crippled.

She's a dwarf/midget.

He's emotionally disturbed/mentally ill.

She's confined/wheelchair bound

He's in special ed.

She's developmentally delayed.

Normal or healthy kids.

Is non-verbal

Client, consumer, recipient, etc.

Birth Defect

Brain Damaged

Handicapped parking, hotel room, etc.

She has problems/special needs

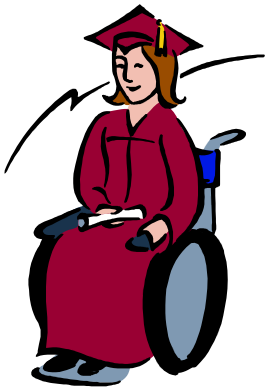
# Transition Services for Students with Disabilities

## ***What Are Transition Services?***

Transition Services are a coordinated set of activities for youth with disabilities that promotes movement from school to post-school activities including postsecondary education, vocational education, integrated employment (including supported employment), continuing and adult education, adult services, independent living, or community participation. Transition services are based on individual needs of the student taking into account the student's preferences and interests and includes instruction, related services, community experiences, development of employment, and other post-school living objectives and if appropriate, acquisition of daily living skills and functional vocational evaluation.

## ***Who Receives Transition Services?***

A statement of the transition service needs that focuses on the student's course of study must be developed for each student with a disability. Beginning at age 16, a statement of needed transition services including, if appropriate, a statement of the interagency responsibilities or any needed linkages must be included on the IEP. The IEP must also include a statement that the student has been informed of procedural safeguards.



## ***What Can Transition Services Do To Help Youth With Disabilities?***

Transition services help youth with disabilities develop the skills and plans to get additional help from adult service agencies. Making these connections before graduation is important.

## ***How Are Transition Services Identified?***

Identifying transition service needs begins with a conversation between the student, the student's parents, and school personnel about the student's career goals and interests. Needed services and supports are then determined to meet those career goals, interests, and preferences. These services and supports may include:

- Assessments:
  - Vocational
  - Functional behavior
  - Interest inventories
  - Learning styles
  - Assistive technology
- Specialized Instruction or Training
- Community-Based Work Experience

On-the-Job Training

### ***Who Should Be Involved in Transition Planning?***

The student, family, special educator, guidance counselor, vocational educator, vocational evaluator, therapists, adult agency service providers, and others that the family or school identify are possible members of the IEP transition planning team. Students must be invited to participate in transition planning. The transition services must be based on the student's needs, interests, and preferences.

### ***What Questions Should Be Asked When Planning Transition Services?***

- What are the student's needs, interests, and preferences?
- What are the student's future hopes, goals, and dreams for independence after leaving high school?
- What activities and services are needed to prepare the student to reach those goals?
- Who should be involved in the IEP transition planning?
- When should adult services and agencies be included in IEP transition planning?

Are specialized supports needed to achieve desired results?

### ***How Do I Find Out More About Transition Services?***

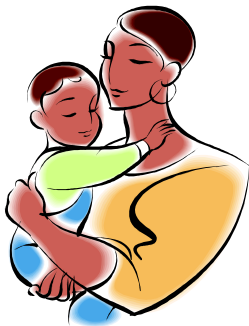
Talk to the special education teacher, guidance counselor, or Families Helping Families Region 7 at 318-226-4541 or 1-877-226-4541. Contact the **special education director** in your district or Louisiana Rehabilitation Services at 318-676-7160.

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## **Early Intervention (Part C of IDEA)**

### **What is Early Intervention?**

Early intervention is the process of providing services, education and support to young children who are deemed to have an established condition, those who are evaluated and deemed to have a diagnosed physical or mental condition (with a high probability of resulting in a developmental delay), an existing delay or a child who is \*at-risk of developing a delay or special need that may affect their development or impede their education. The purpose of early intervention is to lessen the effects of the disability or delay. Services are designed to identify and meet a child's needs in five developmental areas, including: physical development, cognitive development, communication, social or emotional development, and adaptive development.



Early intervention programs and services may occur in a variety of settings, with a heavy emphasis on natural environments. These programs and/or services are proven to be most effective when started as soon as the delay or disability is identified.

Child Find is a component of IDEA that requires states to identify, locate, and evaluate all children with disabilities, aged birth to 21, who are in need of early intervention or special education services.

## Natural Environments

Part C of IDEA requires *"to the maximum extent appropriate to the needs of the child, early intervention services must be provided in natural environments, including the home and community settings in which children without disabilities participate."* (34 CFR §303.12(b))

By definition, natural environments mean *"settings that are natural or normal for the child's age peers who have no disabilities."* (34 CFR §303.18)

The exception to the rule reads *"the provision of early intervention services for any infant or toddler with a disability occurs in a setting other than a natural environment that is most appropriate, as determined by the parent and the individualized family service plan team, only when early intervention cannot be achieved satisfactorily for the infant or toddler in a natural environment."*

The provision of early intervention services taking place in natural environments is not just a guiding principle or suggestion, it is a legal requirement.

## Part C of IDEA: The Early Intervention Program for Infants and Toddlers with Disabilities

Congress established the Part C (Early Intervention) program in 1986 in recognition of "an urgent and substantial need" to:

- enhance the development of infants and toddlers with disabilities;
- reduce educational costs by minimizing the need for special education through early intervention;
- minimize the likelihood of institutionalization, and maximize independent living; and,
- enhance the capacity of families to meet their child's needs.

The Program for Infants and Toddlers with Disabilities (Part C of IDEA) is a federal grant program that assists states in operating a comprehensive statewide program of early intervention services for infants and toddlers with disabilities, ages birth through age 2 years, and their families. In order for a state to participate in the program it must assure that early intervention will be available to every eligible child and its family. Also, the governor must designate a lead agency to receive the grant and administer the program, and appoint an Interagency Coordinating Council (ICC), including parents of young children with disabilities, to advise and assist the lead agency. Currently, all states and eligible territories are participating in the Part C program. Annual funding to each state is based upon census figures of the number of children, birth through 2, in the general population.

In 2004, President Bush signed legislation reauthorizing IDEA. The current IDEA 2004 Statute (P.L. 108-446) for Part C (PDF) contain many requirements states have to meet, including specifying the minimum components of comprehensive statewide early intervention system. States have some discretion in setting the criteria for child eligibility, including whether or not to serve at risk children. As a result, definitions of eligibility differ significantly from state to state. States also differ concerning which state agency has been designated "lead agency" for the Part C program. In fact, statewide early intervention systems differ in many ways from state to state. (source)

## Evaluation and Assessments

Under IDEA, evaluation and assessments are to be provided at no cost to the parent. *Evaluation* refers to the process used by the multidisciplinary team (qualified people with training and experience in the areas of speech and language skills, physical abilities, hearing and vision, and other important areas of development) to find out whether or not your child is eligible for early intervention services. As part of the evaluation, the multidisciplinary team will observe, interact, and use other tools or methods to gather information on your child. These procedures will help the team find out how your child functions. The team will then meet with you to discuss whether the findings mean that your child is eligible for services under Part C.

## **Eligibility for Part C**

Part C eligibility is determined by each state's definition of developmental delay and whether it includes children at risk for disabilities in the eligibility formula. An important part of the evaluation process for infants and toddlers (ages 0 - 36 months) includes informed clinical opinion of professionals experienced with the development of very young children. States have been given a lot of discretion for determining eligibility for entry into their programs. If your child is determined to be eligible, the next step is to create an IFSP.

### ***The Individualized Family Service Plan (IFSP)***

An Individualized Family Service Plan (IFSP) documents and guides the early intervention process for children with disabilities and their families. The IFSP is the vehicle through which effective early intervention is implemented in accordance with Part C of the Individuals with Disabilities Education Act (IDEA). It contains information about the services necessary to facilitate a child's development and enhance the family's capacity to facilitate the child's development. Through the IFSP process, family members and service providers work as a team to plan, implement, and evaluate services specific to the family's concerns, priorities, and available resources. (source) A service coordinator then helps the family by coordinating the services outlined in the IFSP.

### ***The State Interagency Coordinating Council (SICC)***

Each state has a State Interagency Coordinating Council (SICC). According to IDEA, the function of the ICC is to *"advise and assist the lead agency in the performance of the responsibilities set forth in Section 635(a)(10) of the Individuals with Disabilities Education Act, particularly the identification of the sources of fiscal and other support for services for early intervention programs, assignment of financial responsibility to the appropriate agency, and the promotion of the interagency agreements; advise and assist the lead agency in the preparation of applications and amendments thereto; advise and assist the State educational agency regarding the transition of toddlers with disabilities to preschool and other appropriate services; and, prepare and submit to the Governor and to the Federal Secretary of Education on the status of early intervention programs for infants and toddlers with disabilities and their families operated within the State."*

### ***Transitioning out of Part C and into Part B (Special Education)***

Your team (including parents) should start preparing the child for transition (if applicable) into Part B services around the age of 30-32 months (and no less than 3 months prior to the child's 3rd birthday). *All children will not be eligible to enter into preschool special education programs.* A transition planning meeting will be held to discuss next steps, particularly, how to prepare your child for the transition out of Part C. An IEP is held which determines the services that your child will receive after the transition.

To learn more about Early Steps Louisiana's Early Intervention Program call 318-226-8038 or Families Helping Families Region 7 at 318-226-4541 or 1-877-226-4541.



## Northwest Louisiana Aging and Disability Resource Center (ADRC)

A trusted place for information and counseling on all available long term care support options for seniors, disabled adults and their caregivers.

### We Can Help....

- With crisis intervention
- With applications for the Prescription Assistance Program
- With Medicare counseling and assist with Part D selection
- Make it easier to find health and social support options
- Support families in their efforts to care for their loved ones.
- Streamline and simplify the eligibility process for various programs.
- Target individuals who are at imminent risk of being institutionalized.
- Ensure that clients understand their long term care option.

### Parishes Served....

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

All of our services are free.....



### Prescription Assistance Program (Louisiana SeniorRX)

- You may be eligible to receive FREE Medicine.....
- If you are a senior or disabled adult.
- If your income is at or below \$29,400 annually (\$2,450 monthly) if you live alone or \$39,600 annually (\$3,300 monthly) if you live with someone else.
- When you reach your coverage gap in Medicare Part D.

All of our seniors are free!

Just Ask!

For more information about their services contact them at 318-632-5900 or 1-800-793-1198.

## **A Note from your Region 7 LaCAN Leader**

We have been active the past two months with Action Alerts to our Legislators in Region VII who are key committees. We had an Action Alert to the Governor also about new NOW slots and Consolidation and Closure of Developmental Centers.

These "Action Alerts" are very important to act upon; this is our easiest means to keep our Legislators informed of our issues. I urge everyone to take a few minutes when they come out to cut and paste and if you wish to add personal stories to the letters please do.

This year I plan to do a "LaCAN Can Do" contest, each time you do an Action Alert and confirm it with Kay or myself, if you attended the Round Table, come to LaCAN events like workshops or to the Disability Rally, your name will be put in a container and at the end of June I will draw a name out for a 1<sup>st</sup> Place prize, 2<sup>nd</sup> place and 3<sup>rd</sup> place. The more you are active you increase your chance of winning.

I plan to set up meetings in each of the Parishes to meet and greet the LaCAN members and let you see who I am. I am still planning these meeting so I will let you know when and where and what time.

**Join hundreds of "Freedom Rider" advocates as we convene on the Capitol Steps**

## **Disability Rights Rally 2009**

May 7, 2009

12:30 - 2:00 p.m.

For more information about our Disability Rights Rally 2009 or to R.S.V.P. for a ride or T-shirt, please contact Duane Ebarb at 318-688-4830 or [dke1949@bellsouth.net](mailto:dke1949@bellsouth.net). A \$5.00 deposit is required to reserve your seat on the bus; it will be given back to you the day of the rally.

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## **The Cost Effective Use of Funds To Serve People with Developmental Disabilities**

### **What Legislators Can Do in the 2009 Legislative Session**

Support Speaker Pro Tempore Karen Carter Peterson's Amendment to House Bill 1 for an additional 2,000 New Opportunities Waiver (NOW) slots for people on the waiting list.

- Funding for these slots in FY2010 is available in the NOW Trust Fund.
- Funding for the continuation of these slots in FY2011 will be available through savings realized by implementation of OCDD's new assessment and planning process.

### **Why Do This?**

- Over 9,500 people continue to wait nine years for the waiver services they need now.
- Individuals and families should not be denied waiver services they desperately need when money is available in the NOW Trust Fund that is not being used.
- Without waiver services, many families eventually reach the end of their emotional, physical and/or financial ropes and seek out-of-home placement. This costs the state more money and breaks up families.
- Maintaining the FY2010 fiscal effort in the NOW program will fund the continuation of the 2,000 new slots in FY2011 (i.e., no increase in the FY2010 budget amount for NOW services in FY2011).
- OCDD's new assessment and planning process is already bringing the average cost of the NOW down. Costs will be reduced even further with implementation of the Resource Allocation Model. OCDD calculated an average cost of the 2,025 new NOW recipients to be \$44,208. This is significantly lower than the current average cost of \$70,000. According to OCDD, implementation of Resource Allocation will begin with all existing NOW recipients 7/1/09.

## A Note from the Director



I would like to take this opportunity to thank all of the families and professionals in Region 7 for making our first year a success. Because of your support Families Helping Families Region 7 has been able to secure more funding from the Louisiana State Department of Education which will enable us to work with more students with disabilities and their families. We are asking for your continued support in making our next year bigger and better. Thanks you!

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### 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 1.877.226.4541 or email: [fhfregion7@bellsouth.net](mailto:fhfregion7@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!

## Board of Directors

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Parent

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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](http://www.laddc.org)

**Families Helping Families Region 7 programs and this newsletter are supported by the Louisiana Developmental Disabilities Council and Louisiana State Department of Education.**

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