

Families Helping Families

Region 7



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The Disconnecter

By: Claire Savage

I stared at my brother, feeling the frustration on my face. Caleb gazed serenely out the window, mouth slightly open, eyes far away. "Caleb." I said sharply. "Mom said you had to have your work done by the time she gets home." He didn't seem to hear me, but he must have. In one ear and out the other?



"Hey Claire guess what?" the words came out quickly. "Did you know that toys, they have brains, too? They think just like us. It's true." "Okay. Do your work" I said, struggling to regain control over my annoyance. He looked out the window. I heaved a sigh. Caleb was disconnected, and autism was the disconnecter.

I got up and looked through the teacher's daily report on Caleb's behavior, my duty while babysitting. *Caleb was sent to the office today*, it read. *Had trouble controlling his anger at recess.* "Caleb!" I cried sharply. "Did you get sent to the principal's office today?!" "Yes," he said, matter-of-factly. "I hit James." "You WHAT?! Caleb, oh my GOD, that's really bad! You know, kids can get kicked out of school for fighting!" I was angry, so angry. All my life I'd struggled and pushed to be the top of my class, to earn flawless grades. All my life I'd been stricken with guilt should I get in trouble or do something wrong.

All my life, I'd be frustrated if I wasn't as good as the other kids in gymnastics or swimming, then work my butt off until I made it to where I wanted to be. I *cared*. And here he sat, not knowing or caring that he was failing language arts, had atrocious handwriting, never minded getting in trouble, and never bothered to do his homework or brush his teeth because it didn't matter to him. His peaceful expression infuriated me.

"Who'd you hit?" I hissed. "James, I told you!" "James who?" I asked through gritted teeth. "James Samson." "You hit *James Samson?!?*" My voice went up three octaves and the breath whooshed out of my lungs. I knew I was being selfish, but Jenna Samson was the second most popular girl in my school. If she ever, ever, found out my little brother beat up hers, what then? "I can't believe you Caleb." I said in a clipped voice. His face scrunched up. I ran up stairs, not caring whether he did his homework or not.

My dad came home from work an hour later. He knocked on my door. "Did you know Caleb hit someone today?" I asked, still furious. "Did you hear the whole story?" He replied, raising his eyebrows. I sat still in stony silence, waiting. "You know Caleb's friend, Brian? He's pretty popular, but he has an ear implant. Caleb knows him from speech therapy. Brian's the only friend he has in school, and, well, James is not very nice to Caleb." I waited. "Apparently, this James kid was teasing Brian about something little, and, well, you know your brother."

Hot shame filled my stomach. I was close to tears. I had thought Caleb was disconnected, but I was dead wrong. He was probably more connected than the rest of us, with morals, values, love, family and friends. He may not care if he failed out of school or placed last at a swim meet, but he knew what was really important – supporting a friend. He always knew, in the end.

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 fhfregion7@bellsouth.net www.fhrefion7.com

Summer Activities for Children with Disabilities

By: Patti McQuillien

Summer can be a challenging time for children with disabilities. The reason for this include: pools are not equipped to accommodate children in wheelchairs, and on crutches. In addition, parents must remain vigilant as children with poor social skills may become targets for bullies and controlling peers.

It is best for parents to find play areas and pools specializing in helping children with disabilities. Some schools for children with disabilities offer summer programs. Look into these and see if they offer open play times and days. Do they host special events? Check for fees, supervision and range of ability with equipment.

Summer camps are a dream for almost every child. There are camps for children who cannot physically or emotionally handle the demands of a traditional camp. Easter Seals is a non-profit organization that operates a camp parents may wish to consider.



Equine camps are another great opportunity. Horses, and specially trained staff, handle the challenges children with disabilities face. A unique relationship develops between the horses and the children. They build confidence, muscular strength and create memories that last a lifetime.

Baptist and Presbyterian churches offer the most financial help for families who cannot afford the full cost of camp. In addition, many camps have their own financial aid available. Contact non-profit groups and organizations for the names of camps for children with disabilities. Specialized schools may also have information.

At the playground, look for swings with a supportive seat and lap belt. These do not go high like the regular ones and offer a full seat for the child to sit in versus the ones with only a strip of material and two chains. Check the weight limit before placing the child in the swing. Parks are becoming more open to children with special needs.

Water play can be dangerous for children with hearing aids and limited mobility. Water makes surfaces slippery and they can fall as a result. Hold on to children and be prepared to get wet. They will probably get a kick out of this; thereby, increasing their fun!

You can also have them sit on a shower curtain, on the grass for more comfort, and use your finger to create a variety of sprays. My children enjoy big ones that splash smaller drops and they like the "carwash." This is when they pretend to be cars driving through a carwash. I splash them, pretend to "soap" them with bubbles, and rinse with a big spray!

When temperatures rise, and the humidity too, have fun inside with games and books. Act out favorite scenes and imitate characters. Play a guessing game and relax with a short movie or show. Listen to the radio and sing favorite songs.

These activities help children focus, show their skills, develop a tolerance for waiting for a turn and offering positive feedback. They often enjoy being the center of attention for a few minutes. This is especially true when praise follows attempts to socialize.

Here are a few websites offering more information for children with disabilities.

<http://www.shreveportla.gov/dept/spar/index.htm>

<http://www.sbfamilies.com>

<http://www.autism-society.org>

<http://nwlafca.org/SummerCamp.lsp>

<http://camppage.com/louisiana.htm>

<http://www.easterseals.com/>

<http://www.ymca.net/>

<http://www.childrensdisabilities.info/>

www.summercampsinfo.com/categories/special-needs-summer-camps.asp

The article was reprinted from www.hubpages.com.

Inclusion: Has It Gone Too Far?

Inclusion of all children with disabilities in regular classrooms seems to be the law of the land. But is it the right thing for all kids? And how are teachers handling it?

Inclusion -- the idea that all children, including those with disabilities, should and can learn in a regular classroom -- has taken firm root in many school systems, although it is not specifically required by law.

To oppose inclusion would seem to advocate exclusion. Yet, some observers maintain that full inclusion isn't always the best way to meet student needs. Critics of full inclusion ask whether even students with the most severe disabilities benefit from placement in regular classrooms.



Further, some outgrowths of inclusion involve rethinking the structure of the regular classroom. Inclusive classes may require more than one teacher. And teachers and students may need specific technology to help students with disabilities perform better.

While few educators oppose inclusion completely, some express reservations about how full inclusion works in the classroom. Albert Shanker, writing for the American Federation of Teachers in 1996 in "Where We Stand," asserted, "What full inclusionists don't see is that children with disabilities are individuals with differing needs; some benefit from inclusion and others do not. Full inclusionists don't see that medically fragile children and children with severe behavioral disorders are more likely to be harmed

than helped when they are placed in regular classrooms where teachers do not have the highly specialized training to deal with their needs."

Despite the debate over inclusion, how far it should go, and how much it should cost, the latest developments in special education, to some observers, offer more cause to celebrate than to despair. A November 4, 1996, *Time* magazine article titled "The Struggle to Pay for Special Education" summarizes the current state of special education this way: "The good news is that huge strides have been made to improve the plight of special-needs students." The question now being asked,' says Judith Heumann, U.S. Assistant Secretary of Special Education and Rehabilitative Services, "is how we can do it, as opposed to should we do it."

Federal law still requires that a full continuum of placement options be available to each special education student and that placement decisions be made by the Individual Education Program (IEP) team, based on the student's needs. Congress and the courts, however, have affirmed the legal right of children with disabilities to be educated in the least restrictive environment possible. To many, that means "full inclusion," with all students belonging in regular classrooms. To others, it means full inclusion for some children with disabilities and for other children with disabilities a different approach. *This article was reprinted from Education World.*

For more information on inclusive please contact Monica Sullivan, education specialist at 318-226-4541/877-226-4541 or email her at edspecialist@att.net.

Transition Planning for Teens with Disabilities

By: Pamela Wilson

Adolescents and young adults with disabilities, chronic health conditions or other special needs face the same issues as their mainstream peers as they prepare to leave school for work, adult programs, and post-secondary education. Families of teens with developmental disabilities should be aware of guardianship issues that can raise unexpected obstacles related to information sharing, health care and other decisions when their son or daughter turns eighteen.

In addition to the challenges faced by their siblings and mainstream friends, a young person with a developmental disability, physical challenge or medical condition may have access issues and may require support in achieving their goals in further education, finding or keeping a job, managing transportation, dealing with medical professionals, and maintaining an independent or supported living situation.

They deserve to have a circle of friends in their mainstream lives and peer support from people with the same or similar challenges due to disability so they can complain and commiserate with people who already understand their daily experiences - including their relationships with us.



My son mentioned in an off-hand way this week that other people in his independent living group had issues with their families, too. He reminded me that we all may assume an idealized version of other people's lives unless we share our stories, and that it can be tremendously reassuring to learn that our peers have their own share of struggles, too.

Many years ago I considered that my son and his peers might start an email or community discussion group about their challenges with us, in reverse of the disability support groups I knew. Now that the time has come I realize that I did not expect any such thing. I feel fortunate that my parents taught me to exercise a sense of humor in being a mom - although I started to interpret my mom's wish that I had children just like me differently during their early teen years.

Parents, educators, transition specialists and government employees may have worked together on a student's behalf preparing for a transition to a school, job, training program or new living arrangement to find that what they achieved is not a good match for the young person as they mature past their earlier goals and plans.

While this often happens with mainstream teens and young adults, it may be more difficult for a young person with a disability and support needs because the rest of the planning team may have so much invested in the outcomes we have worked so hard to put in place.

Person-centered planning can help young people with developmental disabilities visualize how short term goals can lead to their most ambitious goals, as well as reminding those who are making decisions on their behalf that the individual has a depth of experience, resources and interests to draw upon as they make important transitions.

Like their mainstream peers, young people with disabilities may experience trauma, loss, or depression that derail the most carefully planned transitions to adult life. They may have been 'plugged in' to a near perfect set of living, work, education and support services but be overwhelmed, lose interest, or react with unexpected behavior that is the only way they can communicate unhappiness or anger. A health crisis can change everything.

Transition to adulthood is an open-ended process for all young people. The challenges of adolescence may be resolved during the teen years but there are also physical, emotional and intellectual changes in young adults that may lead to a whole array of new concerns and support needs. They and their mainstream peers are living in a different world than the one we experienced when we were their age. The most important contribution we may be making to encourage and celebrate them as young adults may be the same as when they were children - our individual attention and time spent getting to know them better throughout their lives.

While I encourage parents to find excellent programs and support during our children's transition years, nothing is as important as continuing our relationships with them. Our sons and daughters deserve to be recognized as complicated and contributing adults who will continue to amaze us as they mature into young adulthood and middle age.

Just as mainstream sons and daughters experience their best quality of adult life when they have continuing strong relationships with their parents, our young people with disabilities will benefit from the supportive and changing relationship that develops between other adult children and their parents.

Remember that even parents who seem to have found the best opportunities for their adult sons and daughters with special needs are vulnerable and do experience unexpected set-backs and tremendous challenges. It is important to maintain the support and encouragement we need from one another as we go through challenging as well as joyful times of transition with our sons and daughters. *This article was reprinted from BellaOnline's Special Needs Children Editor.*

For more information on transition please contact Minnie Jenkins transition facilitator at 318-226-4541/877-226-4541 or email her at transitionfhf@att.net.

An Interview with OCDD Assistant Secretary Kathy Kliebert An Overview of Changes in OCDD System

Reprinted with permission from the editors of the TriAngle



Unfortunately, a lot of inaccurate information is circulating around the state regarding several proposed changes to the state's system responsible for serving people with developmental disabilities that are included in the Executive Budget, now House Bill 1. This misinformation makes change even more difficult for the individuals and families who are going through a period of transition.

To ensure that accurate information is available to all those interested in these changes, the *TriAngle* interviewed the Office for Citizens with Developmental Disabilities (OCDD) Assistant Secretary Kathy Kliebert.

The changes include the closure of Northeast Supports and Services Center in Ruston and the transition of individuals with low support needs in the remaining centers to community based services - proposals community advocates have long advocated to implement. OCDD reports that all individuals moving to the community will go through an individual assessment and planning process where appropriate choices will be discussed. The complete interview with Ms. Kliebert is included below.

How would you characterize the proposed changes in OCDD's budget?

The budget meets the needs of individuals with developmental disabilities in a manner that is cost effective and efficient by accessing less costly privately operated community services as an alternative to institutional services. Louisiana ranks eighth best in the nation in overall fiscal effort related to spending for individuals with developmental disabilities, however, the state is not spending these dollars in the most efficient, nor the least restrictive manner. Louisiana ranks first in fiscal effort directed towards institutions – spending 38 percent of its expenditures on institutionalization of people with developmental disabilities compared to the national average of 19 percent. Louisiana has more individuals in ICFs/DD per capita than any other state, almost four times the national average. Furthermore, Louisiana ranks third highest in the usage of large ICFs/DD although compelling literature shows that outcomes are better in smaller facilities, and even better in the community. The budget re-directs state government resources to building community capacity in a manner consistent with consumer choice, evidence based practices and national trends.

Why was Northeast Supports and Services Center in Ruston selected for consolidation with Northwest Supports and Services Center?

When we looked at our centers, Northeast had abuse/neglect issues and clinical staff shortages that we haven't been able to successfully resolve. There were also ongoing management issues that could be addressed through the consolidation with Northwest.

Where will the Northeast residents be moved and what level of supports will be provided for them?

We will individually assess each person to determine if their level of need requires the supports provided by a supports and services center. Those that do will transition to Northwest or Pinecrest, depending on which center can best meet their needs. We will also take into consideration where their families reside. Those individuals who pose a risk to themselves or others will receive the necessary supervision in the supports and services center. The remaining residents will receive the supports they need to live successfully in the community.

Individuals with the two lowest levels of support needs in all the supports and services centers will transition to community based services. Please explain the process OCDD is using to assist individuals and their families in choosing the community services that best meet their needs.

As a starting point, residents will be assessed using the Support Intensity Scale (SIS) to identify those individuals who don't need the level of supports provided in a supports and services center. We will involve the individual and their family in exploring available options – waiver services and private community homes.

Will your office follow residents once they move into the community to ensure they receive quality services?

Yes. Once the individual moves our staff makes quarterly visits and provides transition support and technical assistance to the private provider for one year. This transition support team is in place to not only ensure the health and safety of the individual but also their quality of life. All of these processes were used successfully in the downsizing/closure of Metropolitan Developmental Center in the Greater New Orleans area.

Moving individuals out of the state's institutional settings into the community is not new to Louisiana – your office has been downsizing its centers for many years and has already successfully closed two centers. Based on your past experience, do you have any doubt that the individuals who will move can be better served in the community?

Absolutely not. We have tracked individuals after they have left our institutions and in most cases they have increased their satisfaction. Community-based settings not only allow residents more options for individualized care, but also allow them to interact more frequently with family and friends and others in the community.

OCDD is currently implementing the Resource Allocation Model in the New Opportunities Waiver which allocates services according to an individual's assessed level of need. In many cases, waiver recipients' service hours are being reduced to accurately reflect their level of need. Is the transition of the center residents to the community an indication of the department's policy to implement resource allocation fairly across all settings?

Yes, we will be using the same instrument and the same process in our supports and services centers to determine the level of need of the residents and working with them and their families to transition them to a less costly and more appropriate community based setting.

Acadiana Supports and Services Center in Iota will be privatized, not closed. Please explain the process that will be used to ensure the residents will receive the same level of care they are currently receiving.

Our office will utilize a Request for Proposals process to obtain a private provider that will meet the department's requirements for quality, health and safety. We will work with the parents' association to ensure that the provider will meet their expectations to assure their family member continues to receive high quality supports. As part of the contract process we will include monitoring of individual outcomes and selected quality indicators.

In response to budget cuts in January 2010, OCDD privatized all of the state's community homes for people with developmental disabilities. Is that working out as well as you had anticipated?

Yes, it's working well. We are on target to transition the majority of people by April 30th.

How many of those people have chosen waiver services and how many ICF/DD beds have been abolished?

Twenty-five people to date have chosen waiver services and 92 ICF/DD beds will be abolished.

Is there anything else you would like to add?

This budget will assist in the sustainability of services for people with developmental disabilities and includes opportunities that will increase the quality of life for those citizens.

It's Hurricane Season...Are You Prepared

The 2010 Hurricane Season has started. Individuals with developmental disabilities and their families need to prepare now if an emergency should occur. Here are some steps to follow if you need to evacuate.

- If a family member needs assistance with evacuation, register with local emergency authorities **Homeland Security at 318-425-5351** before hurricane season begins. Emergency response crews will not be able to help you when the storm arrives.
- Register with your local power company. Most companies do give special priority to homebound patients but it may take time before crews can begin work.
- Make prior arrangements with your physician and medical supplier if you require medical devices that operate on electricity.
- If you require oxygen, check with your supplier about emergency plans.
- If you have to evacuate, make sure to bring any medications, special equipment, walkers, wheelchairs and other aids, along with written care instructions.
- Help those with special needs by preparing their homes and property for emergencies, shopping for supplies and writing a disaster plan.

If you move to a Medical Special Needs Shelter, remember to take:

- Medications and equipment needed to administer
- Written instructions regarding your care
- Walker, wheelchair, cane or other special equipment
- Bedding
- Identification, insurance, health and Social Security cards
- Batteries
- Nonperishable food including that needed for special diets (five [5]-day supply)
- Personal hygiene items
- Clothes
- Air mattress
- Drinking water (one [1] gallon per day)
- Extra glasses
- Flashlight
- Garbage bags
- Food for guide or service dogs (if applicable)
- Style and serial numbers for medical devices (such as pacemakers)
- Draw sheets (if appropriate)
- Plastic hospital-type urinal (if needed)

A caregiver must stay with a special needs family member while in the shelter.

The Take and Go Emergency book was developed by individuals and their families with developmental disabilities and should be used to record all emergency information.

If you would like a book or further information contact Mary Russell OCDD family facilitator at Families Helping Families Region 7 at 318-226-4541/877-226-4541 or ocdd@att.net.

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 318.226.4541/1.877.226.4541 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!



The Louisiana Family to Family Health Information Center

Schedule a workshop with us and we'll send you all the materials you'll need. Then, we'll call you at a convenient time for you. We'll present the workshop just as if you were there in person and answer your questions. Available workshops: (Don't see something you want? Call us.)

What is the F2FHIC (Family to Family Health Information Center)?

Learn all about this program and what it offers families of children and youth with special health needs, behavior disorders, mental health issues and disabilities.

What is a Medical Home?

Learn about this new way to deliver medical services to provide your child better care.

Individualized Health Plans at School

Do you know what they are? Do you know if your child needs one? If not, this workshop is for you. Who should attend: parents of children on medications that can have any side effects at school, children with diabetes, seizure disorders, asthma, who have feeding tubes, who need medical procedures done while at school or medication administered at school...to name a few.

H1N1 and Pandemic Flu events

What is a pandemic? What's the status on H1N1 and how to prevent infection as well as prepare for a community devastated by pandemic flu.

Family Opportunity Act Medicaid

Louisiana's Medicaid Buy-in program for children with disabilities. Learn how it works and if you might qualify.

Emergency Preparedness for CYSHCN

An all-hazards approach to emergency preparedness for families of children and youth with special health care needs. Don't delay... make your plan today.

Health Coverage for Adult Children to Age 26 on Parent Insurance

Unraveling the new health reform and insurance coverage for adult children up to age 26.

Coming to Terms...

A supportive atmosphere for families of children and youth newly diagnosed or unable to move past feelings of grief after receiving diagnoses for their children. This workshop looks at the phases of coming to terms and moving past the grief stage toward advocacy.

Advocacy Avenues

Opportunities in Louisiana for you to make a difference for children and youth with disabilities and special health needs.

"Who Can Help My Family?"

A resource training on programs available which provide assistance for families of children with disabilities and special needs. Learn the ins and outs of these programs and take away a resource guide to refer to later.

"How Can I Help My Family?"

A leadership skills and advocacy training to help families partner with their professionals in meaningful ways to achieve better outcomes for kids

July, August, and September 2010

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***To learn more
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1-800-331-5570
and ask for
Karen***



The goal of EarlySteps is to help families ensure their infants and toddlers receive services now to help them in the future. Every family with a child age birth to three years with a disability or a developmental delay may be eligible for services provided by the EarlySteps Early Intervention System. All families served by EarlySteps are guaranteed these rights by federal law and regulations under Part C of the Individuals with Disabilities Education Act.

As a parent with a child in EarlySteps you have certain Rights. Prior Notice, Evaluation/Assessment, IFSP, Consent, Privacy, Records Review, and Confidentiality are a few. Along with those rights there are also certain roles and responsibilities. Parents must first familiarize themselves with the EarlySteps Parent's Rights Statement. This document is given at intake.

Other roles and responsibilities include:

- Participate in the IFSP process—work with service providers to plan and carry out goals for your child, and share your knowledge and observations with them.
- Schedule your visit during times that are best for your child and family. Be present and actively participate in all visits.
- Be on time for scheduled appointments and notify your service provider when you are unable to keep an appointment. Provide reasonable notice if you need to cancel or reschedule a visit.
- Write down any questions you may have and be prepared to discuss what has happened since your last visit.
- Ask to be shown anything you do not completely understand and practice the strategies together during the visit.
- Review the monthly Explanation of Benefits.
- Use the strategies throughout the day with your child and make notes of what is working and what is not.
- Be open and honest with your service providers. Don't be afraid to ask questions or tell the service provider if something is not going well.

For more information on your Rights, Roles, and Responsibilities Families Helping Families Region 7 offers a Free EarlySteps Parent Orientations monthly, or you can contact Monica Stampley, EarlySteps Community Outreach Specialist, at 318-226-4541 /1-877-226-4541 or email her at monica.stampley@la.gov.



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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

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

