

ALABAMA COUNCIL FOR DEVELOPMENTAL DISABILITIES

# **ACDD***Advocate*

Volume VI Number 4, Winter 2012

**'Bringing  
the sunshine' on  
ALABAMA'S  
GULF COAST**



# THE FEDERAL DEFINITION OF *Developmental Disability*



## **A. The term “developmental disability” means a severe, chronic disability of an individual that is:**

- attributable to a mental and/or physical impairment
- is manifested before the individual attains age 22
- is likely to continue indefinitely
- results in substantial functional limitations in 3 or more of the following areas of major life activity:
  - (1) self-care
  - (2) receptive and expressive language
  - (3) learning
  - (4) mobility
  - (5) self-direction
  - (6) capacity for independent living
  - (7) economic self-sufficiency
- reflects the individual’s need for a combination and sequence of special, interdisciplinary, or generic services, individualized supports, or other forms of assistance that are of lifelong or extended duration and are individually planned and coordinated.

## **B. Infants and young children:**

An individual from birth to age 9, inclusive, who has a substantial developmental delay or specific congenital or acquired condition, may be considered to have a developmental disability without meeting 3 or more of the criteria (listed above) ... if the individual, without services and supports, has a high probability of meeting those criteria later in life.



From the Developmental Disabilities Assistance and Bill of Rights Act, 2000 Reauthorization, Public Law 106-402, S. 1809-7(8).



# ACDD Advocate

Vol. VI, No. 4

Winter 2012

The ACDD Advocate is published quarterly by the Alabama Council for Developmental Disabilities.

## COUNCIL OFFICE:

### RSA Union Building

100 North Union Street

P.O. Box 301410

Montgomery, AL 36130-1410

(334) 242-3973 or 1(800) 232-2158

FAX: (334) 242-0797

Website: www.acdd.org

## ACDD STAFF:

**Elmyra Jones**, Executive Director

**Debra Florea**, Information and Referral

**Shunqulla Moore**, Office Manager

**Sophia D. Whitted**, Fiscal Manager

## COUNCIL MEMBERS:

**Dr. Dave Martin**, Chair, Parent Advocate

**Peggy Givhan**, Department of Senior Services

(Designee)

**Johnna Breland**, Parent Advocate

**Ruth Brewbaker**, Parent Advocate

**Vivian Brown**, Self Advocate

**Sue Berry**, Department of Human Resources

(Designee)

**DaLee Chambers**, ALSDE – Special Education

(Designee)

**Michael Collins**, Self Advocate

**Wendy Dean**, Self Advocate

**Karen Driver**, Parent Advocate

**Stefan Eisen**, Parent Advocate

**Joe Eversole**, Self Advocate

**Amy Floyd**, Department of Children's Affairs

(Designee)

**Beverly Gardner**, Parent Advocate

**Mitchell Garrett**, Epilepsy Foundation

**Ellen Gillespie**, Alabama Disabilities Advocacy

Program

**Carolyn Greene**, Parent Advocate

**Reginald Guilford**, Self Advocate

**Linda Hames**, Rehabilitation Services (Designee)

**April Ikner**, Self Advocate

**Charlie Jordan**, Parent Advocate

**Acquanetta Knight**, Department of Mental

Health, (Designee)

**Walden Lechner**, Self Advocate

**Jacqueline Harris**, Department of Public Health

(Designee)

**David Lowry**, Self Advocate

**Angela Jones McNeal**, Parent Advocate

**Frances Murphy**, Family Member

**Latonda Cunningham**, Alabama Medicaid Agency

(Designee)

**Gaylen S. Pugh**, Local Agency

**Nancy Rhodes**, Parent Advocate

**Sylvia Richey**, Self Advocate

**Graham Sisson**, Governor's Office on Disability

**Shelia Smalley**, Family Member

**Joan Smith**, Self Advocate

**Scott Sligh**, Parent Advocate

**Cindy Sweeny**, Center for Excellence (Designee)

# Bringing the sunshine, on ALABAMA'S GULF COAST

7



## Pirates Cove Marina and High Hopes School

Unique fund raiser is dedicated to supporting school for children with autism.

10



## High Hopes School

School with intense, focused approach to working with students on Autism Spectrum.

10



## Collaboration Enhances ESY Services

Summer Program for Students with Disabilities in Lee County benefits from combined efforts of three school systems.

16



## Council Member Profile

Passionate supporter of children with disabilities shares dream of boating excursions for an underserved community.

28



## Dr. Dennis Campbell of USA

A career grows from street-gang social work to distinguished disability researcher.



## Contents

Letter from the Governor.....	2	Extended School Services.....	15
Letter from the Council Chair.....	3	Scott Sligh.....	18
Letter from the Executive Director .....	4	Andi the Blogger.....	20
Pirates Cove Marina .....	5	Dr. Dennis Campbell.....	22
Pirates Cove Fundraiser.....	8	Cri-du-chat syndrome .....	25
High Hopes School. ....	10	Carolyn Greene wins award .....	28
Applied Behavior Analysis.....	14	Jessika Burton's tissue dolls.....	29

**DISCLAIMER:** All direct quotations and other information represented through interviews in this magazine are the opinions of the speakers, and do not necessarily represent the position of the Alabama Council for Developmental Disabilities or the Alabama Department of Mental Health.

# Letter *from the* Governor



## STATE OF ALABAMA

Greetings:

There are many reasons we love our state. One of them, of course, is simply the diverse geography of this unique place we call home: the beauty of our farms and fields, the majesty of our mountains, and the sun and sand that brighten our southern shores.

From the wilds of the magnificent Tensaw Delta, to the rich agricultural operations, to its many rivers and creeks and bayous and bays, South Alabama is indeed one of the most beautiful and ecologically-diverse places on Earth. And each year people from across the country set out with this destination in mind, often as part of a tradition that crosses several generations.

In this issue of the *ACDD Advocate*, readers are able to see another side of this wonderful part of our state. Through these stories and profiles, we meet people and families who make up the disability community of our coastal region: teachers, providers, researchers, and friends.

Their stories are as diverse as the lay of the land. In the little town of Elberta, known primarily for its longstanding German heritage and its spring sausage festival, we meet a staff of practitioners at a small school that teaches language and behavior therapy to children with autism. Their enthusiasm and love for their work is matched only by their competence and amazing results.

But how do schools like this manage to keep their doors open? Well, one way is through a fundraiser that combines good times with good information. In tiny Josephine, Alabama, an area of Baldwin County as remote as it is beautiful, Pirates Cove Marina hosts an annual event that raises more than \$50,000 to help the children at High Hopes School. Many of those who support this event have known all four generations of the Mueller family that for 50 years has owned and operated this place that is one of our state's enduring treasures.

On the other end of Baldwin County we meet a City of Fairhope municipal engineer who, with his remarkable wife, is raising two children with disabilities. Nowhere is it more clear that love and hope enable us to see ability rather than disability.

Meanwhile, at the University of South Alabama in Mobile, we meet a parent whose personal experience led him to a distinguished career of research, service and teaching.

I have always known that the finest people in the world call Alabama home. Wherever we go in our great state we will find this to be true. But for now, as the fishing reels ring and children laugh and play in the sand, let's take a moment and get to know a few of our good neighbors from the Gulf Coast.

As I wish to say in every issue, let's all work together to make Alabama the best it can be, no matter the challenges we face in the short term, and let's especially look at a person's abilities and not their disabilities.

A handwritten signature in black ink that reads "Robert Bentley".



STATE OF ALABAMA

# from the Council Chair



**Dave Martin**, Council Chair

## ALABAMA COUNCIL FOR DEVELOPMENTAL DISABILITIES

As many of our readers know, I like to emphasize collaboration. I like to see people and agencies bring together their special passion and expertise and experience to make a given project as efficient, effective, and long-lasting as possible. And of course the idea of effective collaboration is especially important in these times of fiscal crisis.

Recently, I was able to visit some of the people and places that are showcased in this issue of the *ACDD Advocate*. Every person in this issue has a wonderful family story, a personal journey that led them to a deep understanding of both themselves and of people with disabilities. It is inspiring to meet these kinds of people all across Alabama as they go about their daily life and work.

One thing that particularly caught my attention was a kind of collaborative process in which a rustic, bay-front marina raises money in a way that is unique to its own setting. This event – the kind you would only find on Alabama's Gulf Coast – enables a school for children with autism to keep its doors open. Pirates Cove Marina hosts an annual "Illuminating Autism FunRaiser" that combines education and entertainment during a rowdy, country-style weekend that features food, fun and music along with information about autism. And along the way the gang at Pirates Cove raises well over \$50,000 a year to support the High Hopes School in tiny Elberta, Alabama.

High Hopes School, in its turn, provides an outstanding educational program based on Behavior Analysis. The teachers are board certified, and the children thrive in an environment that focuses on the individual. As they say at High Hopes, "motivation is the key, and our teachers are motivated!" The school's director goes on to add that the teachers are in fact so motivated by their work that "they are worth ten times what they make here."

As I have stated many times, professional skills are important to any job well done, but there must also be a strong sense of passion. Along with the remarkable results that were so evident in the young students at High Hopes School, I certainly saw passionate teachers changing lives there.

My point is that here were people from two distinctly different environments – a small but very successful school and a salty marina that has been ingrained in the local landscape for 50 memorable years – doing what they each do best. And yet they find a way to sustain and enrich each other, sharing what they do with a wider public and bringing about awareness, understanding, and acceptance. One message here is that in spite of our different journeys, we are all more alike than we are different.

Collaboration comes in many forms. I was privileged to see good work and good times being enjoyed by so many on Alabama's Gulf Coast. Let's share this spirit wherever our individual journeys lead us.

## ACDD Mission Statement

To promote and support independence, advocacy, productivity and inclusion for Alabamians with developmental disabilities.



# A Letter

from the

## Executive Director



**Elmyra Jones**, Executive Director

### ALABAMA COUNCIL FOR DEVELOPMENTAL DISABILITIES

In our most recent issue of the *ACDD Advocate*, I wrote about Dr. John Thornton and the dental demonstration project that was funded by the Council. I looked at how that program's legacy is still helping young people with disabilities.

Though the grant has expired, the lessons that were handed down to our state's dental students during the course of the grant opened their minds and hearts to the positive power of including people with disabilities in their private practices. More and more often, we are seeing professionals having more inclusive practices. Using the example of Dr. Keri Miller, I tried to show the lasting benefits that can come from a good grant administered by great people. And Dr. John Thornton is one of the great people in Alabama, be assured of that!

While reading in this issue about Dr. Dennis Campbell and his work at the University of South Alabama in Mobile, the same thought came into my mind. I recall years ago how Dennis and I worked together on various projects as part of the Council's work. One particular project allowed him to work with families that had a child with autism. A second part of that grant was developing a secondary transition model called Project CHOICES that helped middle school and high school students and their families navigate the system. Now that Council grant has led to something even bigger.

"We were able to translate that ACDD grant into an Institute for Educational Sciences federal grant from the Department of Education," Dennis recalled in the story. "That \$1.3 million three-year federal grant is ongoing as we speak."

Among other things, this grant will result in a long-term model that helps students and their parents frame meaningful questions for the students' IEPs.

"The original DD Council grant gave us the groundwork to prove that we really had something going," Dennis added. "Without something concrete to show, we wouldn't have been able to win the large federal grant."

Obviously, it is very rewarding to me both personally and professionally when I see our Council invest in projects that help people. It is doubly rewarding to see these projects go on to sustain themselves even after the Council funds are spent. This is just another example of the lasting good that comes from the hard work and wise choices made by our dedicated Council members.

Thanks to everyone who plays a part in helping connect the dots and turning them into large, beautiful pictures.

Famous burgers on a flat-top griddle

# Pirates Cove

*a unique, storied part of Gulf Coast history*



On September 12, 1979, Hurricane Frederic roared into Alabama's Gulf Coast with a 12-foot storm surge and 125 mph winds, completely destroying the Dauphin Island Bridge along with the Gulf State Park hotel and everything else in its path. Frederic was the costliest hurricane to ever hit the Gulf Coast up to that time – which is pretty amazing considering that just ten years earlier Mississippi was famously decimated by Hurricane Camille.

For those who were already familiar with Alabama's Gulf Coast – known to many as “The Redneck Riviera” – the changes wrought by Frederic were almost unimaginable. What had once

been miles of beachfront dotted with small wooden cabins gave way to large condominium developments. Mom and Pop fish camps were replaced by huge restaurants and luxury marinas. Even the back bays and bayous felt a surge of development. In many respects, the post-Frederic Gulf Coast has never been the same.

The sense of rustic remoteness on Alabama's Gulf Coast has certainly dissipated, but there was an upside to the carnage. Frederic has been credited with spurring redevelopment in Mobile and the surrounding coastal region. According to Robert Sheets, director

of the National Hurricane Center, the economic aftermath of Frederic is staggering: Prior to Hurricane Frederic, there was one condominium complex in Gulf Shores. Most of the homes were

**For those who were already familiar with Alabama's Gulf Coast – known to many as “The Redneck Riviera” – the changes wrought by Frederic were almost unimaginable.**

single, individual homes built behind the sand dunes. Today, where there used to be one condominium, there are now at least 104 complexes – not units, complexes. (Congressional testimony, 1992).





***“For one thing, we are still selling the same great cheeseburger that my dad made up,” Mueller said. “We have top-quality ground beef that cooks in its own grease on the steel griddle. We add cheddar cheese, lettuce and tomatoes, onions, and gin sauce on a hearty bun. Lots of people tell us it’s the best burger they’ve ever eaten.”***

At least one place, however, has slipped through the sands of time and remained delightfully untouched. Pirates Cove Marina in tiny Josephine, Alabama is situated on a small, secluded peninsula in Perdido Bay just west of the Florida line, across from Orange Beach and Ono Island, and about ten miles south of U.S. 98, between Lillian and Elberta. Arriving at Pirates Cove by road on Baldwin County 95 means a flat drive through the tall pine forests. Arriving by boat – on warm-weather weekends, at least – means floating up on a party right out of a 1960s Beach Blanket movie.

According to Karl Mueller, who with his mother Eileen and brother Paul own and operate Pirates Cove, this sustained simplicity is more than coincidental.

### **Long family history in Baldwin County**

“My great-grandfather was on the colonization board of Baldwin County,” Mueller said. “He published a German-language newspaper in Chicago – the *Abdenpost* it was called. The paper was published daily beginning in 1889. He and many of his German

friends from Chicago often came here for vacations. My family was in Lillian, but many of them resided in Elberta. That’s why the area has such a strong German culture.”

By 1957, the newspaper had been sold and Mueller’s grandparents had moved to Baldwin County for good.

“My grandparents knew the Lawrence family, who owned the property that still makes up the basic building and grounds of Pirates Cove,” Mueller said. “They traded the proceeds from the sale of the *Abdenpost* as well as their home in Lillian for all of this. You can easily see how rustic it is. We know that Roosevelt’s Civilian Conservation Corps was working in Baldwin County in the 1930s, and many people say the CCC constructed this building, but we don’t have absolute proof of that. Anyway, we’ve been here ever since.”

In those early days, the large, rambling wooden building housed a post office and a general store. The mail boat ran to Josephine every day. But when Mueller’s grandfather died that same year, his wife Elsa, known to all as “Miss Kitty,” and only son, Paul Mueller, were forced to reevaluate what they were up against.

“Growing up in Chicago, my father had basically led a life of privilege as the son of a prominent newspaper publisher,” Mueller said. “Now here he was, 15 years old, living in a drafty house way out on the bayou in coastal Alabama. I’m sure it was a culture shock for both of them.”

But they adjusted. Mrs. Mueller turned her hand toward meal preparation and expanded the general store into a reservation restaurant.

“People would come out here from Lillian, Elberta, and Pensacola to eat,” Mueller said. “There was no menu or anything like that. They just basically knew that on weekends there would be

[www.myspace.com/ILLuminatingAutism](http://www.myspace.com/ILLuminatingAutism)



good food, and they came to enjoy time in the country and on the water. The Mobile and Pensacola Yacht Clubs would also stage raft-ups that included lunch or dinner here in the store."

## **Paul Mueller establishes great burger tradition**

Young Paul grew up fast, and developed a Pirates Cove specialty that is famous to this day.

"Dad set up a flat-top steel griddle and started selling cheeseburgers," Mueller said. "Although we replaced it with a new grill recently, it is the same basic layout as the one he ran for 50 years."

Paul Mueller is a legend in this part Baldwin County, especially to those who knew the place in the days before Frederic. Many a fisherman has motored into a silent slip at Pirates Cove after a tough day at sea to soothe himself with quiet conversation, a sizzling cheeseburger, and a cold draft beer. Neighbors dropped in every day. Paul operated the place for many, many years, establishing its presence as a marina along the way.

"He and mom got married in 1965, I believe, and he began working toward a 100-slip marina out here on the bay-front. But in 2004, when the slips were blown away by Hurricane Ivan, it was the fourth such disaster so we have permanently downsized the marina. Now we just lease spaces to sailboats in a protected area behind the main building. Once people set up here they pretty much hang on to the slip. A few people live on the boats, but most of them essentially function as the owner's private floating condominium."

Aside from slip rentals, the main business at Pirates Cove today is food and bar service.

"For one thing, we are still selling the same great cheeseburger that my dad made up," Mueller said. "We have top-quality ground beef that cooks in its own grease on the steel griddle. We



add cheddar cheese, lettuce and tomatoes, onions, and gin sauce on a hearty bun. Lots of people tell us it's the best burger they've ever eaten."

The crowds come mostly on weekends, though Pirates Cove is open every

***Much of the action at Pirates Cove is outdoors. The enormous beachfront on the beautiful bay is swarming with people throughout the day and into the night. And that includes scores of families with their children playing in the warm sand, with outdoor pavilions and tables set up for their convenience.***

day. In addition to its burgers, Pirates Cove is also known for The Bushwhacker, its signature drink.

"I'd say we do 80 percent of our annual business between April 1 and the end of October, when the weather starts turning cool," Mueller said. "And of that 80 percent, I'd say half of that is done on weekends. So we hit it hard when we have the chance. It's a lot of work, but it can be a lot of fun, too."

One almost has to see the weekend crowd to believe it. All stripes of people

come to Pirates Cove. The regulars – of which Mueller estimates there are well over 100 – call themselves "The Pirates Cove RiffRaff." Gray-bearded hippies mix easily with the bikers and bikini-clad boaters. Large, well-mannered dogs seem to be everywhere. The huge, wrap-around screen porch with vintage picnic tables is always full. Wait staff from the order-at-the-bar kitchen wander through with trays of food loudly calling the customer's name. There is also a bandstand, where music is performed on weekends, and layers of graffiti are scrawled on the old wooden walls. The only real "indoor" dining is a small room adjacent to the kitchen-bar area.

Much of the action at Pirates Cove is outdoors. The enormous beachfront on the beautiful bay is swarming with people throughout the day and into the night. And that includes scores of families with their children playing in the warm sand, with outdoor pavilions and tables set up for their convenience.



*continued on page 9*



Autism awareness and education—

## Pirates Cove hosts annual 'FunRaiser' to support High Hopes School

Every year, on the first weekend after Memorial Day, Pirates Cove Marina sponsors a weekend-long throw-down for hundreds of people that features food, music, games, a drawdown for a new Jeep, and something completely different – an opportunity to support local children with autism who attend High Hopes School in nearby Elberta (*see related stories in this issue*).

"Our daughter Lucia was diagnosed with autism as a young child," said Karl Mueller, who with his extended family owns Pirates Cove. "Through a series of events that neither of us could have dreamed up, my wife Rachael started a school and it has been a life-changer for both her and Lucia. It's a wonderful school that has helped many of our local families."

Soon after Lucia's diagnosis she began therapy in Destin, Florida. The Muellers were uncertain as to how they could afford the treatments. A friend who books the bands at Pirates Cove suggested asking some musicians to come in and play,

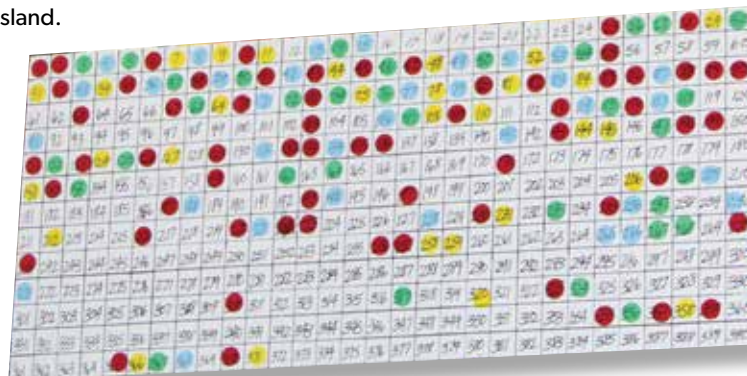
and the first Illuminating Autism Fun-Raiser was, in Rachael's words, "thrown together on a wing and a prayer."

That first event raised \$11,000 that went to help Lucia and some other local children. Two years later High Hopes School had launched and, with the help of an entrepreneur and friend, Tom Schlinkert, Pirates Cove put together a raffle and generally enlarged the scope of the event. The net proceeds more than tripled in the second year. It's now an event that is widely anticipated in and around Pleasure Island.

"We just had our sixth annual event, and we're now clearing about \$65,000 a year. It literally supports our school," Rachael said.

"Our biggest event is a drawdown for a

new Jeep, which is very popular," said Karl. "And maybe just as important as the money, the event also allows us to share with the 'RiffRaff' some information about autism – the incidence rate, how autism affects people, things like that. Almost everyone who comes around here with any regularity has learned a lot, and many people come up to me or Rachael and ask us detailed, involved questions about autism. It's really kind of neat the way the whole thing worked out."





## **'We welcome everyone here'**

They come by car, boat, motorcycle, and jet-ski. The dredged channel is jammed with beached boats, with others idling in line to fill up any vacant spot. Although Mueller works to discourage it, many boaters bring their own drinks and simply order cheeseburgers to eat on board.

"We try to stop it, but there's really not much we can do," he said. "Any way, it just adds to the show."

***"People ask me: why is this place so different? Well, obviously we don't have the kind of polish and 'sameness' that has been a growing part of the scene down here since Frederic. But it's more than that. It's the people who come here, the eclectic crowd. When the sheet-rockers are sitting next to the surgeons, when they're all having fun and not caring who does what, that's what makes it work. That's really what makes us what we are."***

Watching Mueller at work, one realizes the long, deep calm that is required to oversee such a circus that, despite its rowdiness, is also somehow a welcoming family environment.



"We have a great staff," he said. "At the peak of the season we employ probably two dozen people, and several of them have been here for a while. Rick, for example, has been here for at least 25 years. We try to be calm, try to be friendly, and especially try to provide terrific service in a fun environment."

Mueller said it's a mixed blessing to see his family's business grow in popularity.

"It means less time at home with the kids, but you do what you have to do. Besides, I can't imagine a better place to spend every day."

Karl and his brother Paul exemplify the easy-going nature of their business: Karl went to Auburn, his brother to Alabama.

"We welcome everyone," Mueller said. "It's important to carry on the family tradition, but it's also important to help new people make memories. A lot of memories have been made here over the years. We're really just part of something much bigger than ourselves."

"People ask me: why is this place so different? Well, obviously we don't have the kind of polish and 'sameness' that has been a growing part of the scene down here since Frederic. But it's more than that. It's the people who come here, the eclectic crowd. When the sheet-rockers are sitting next to the surgeons, when they're all having fun and not caring who does what, that's what makes it work. That's really what makes us what we are."

That, and Paul Mueller's cheeseburgers on the flat-top griddle.



*Using applied behavior analysis*

# HIGH HOPES School

*shares love, expertise in autism therapy*



**H**igh Hopes School in Elberta, on the Alabama Gulf Coast in Baldwin County, is located on the campus of St. Benedict's School. Its rural setting and relaxed and loving atmosphere belies an intense, focused approach to working with the school's students, all of whom have been diagnosed as being on the Autism Spectrum. The young students are working toward integration into the mainstream classroom, typically at the Kindergarten level. The school's director, Rachael Mueller, still marvels at where she is today.

"I grew up in Lillian, Alabama, just across the Perdido Bay Bridge from Pensacola, and my whole family lives in and around the Lillian-Elberta area," she said. "I majored in Business Management at the University of Alabama and moved back

**Its rural setting and relaxed and loving atmosphere belies an intense, focused approach to working with the school's students, all of whom have been diagnosed as being on the Autism Spectrum.**





here after graduation to begin a series of jobs, none of which held real challenges for me. So I went back to school to study education.”

In April of 2000, Rachael married her longtime boyfriend Karl Mueller.

## A marriage, a discovery

“Karl was just five years old when his grandmother, Miss Kitty, died. When we became engaged Karl gave me her ring. She had gotten this ring for her 25<sup>th</sup> wedding anniversary, and we were both 25 years old at the time, so we thought we were getting into something special. We didn’t know the half of it.”

Karl Mueller himself comes from an old Baldwin County family that owns and operates the legendary Pirates Cove Marina. Two years

**“Lucia just cried and cried all the time,” Mueller said. “We knew something wasn’t right but we didn’t have any idea what it was. The pediatrician said she’s fine but deep down I knew better.”**

into their marriage the Muellers had their first child, Jackson, and in 2003 they welcomed a daughter named Lucia.

“Lucia just cried and cried all the time,” Mueller said. “We knew something wasn’t

right but we didn’t have any idea what it was. The pediatrician said she’s fine but deep down I knew better.”

At Mueller’s insistence, the pediatrician agreed to refer Lucia to a speech pathologist.

“That was the first time I heard the word ‘autism’ in a real medical sense, and it was in reference to our daughter,” Mueller recalled. “I felt like I had been kicked in the gut. But that was the only time I have felt that

way, before or since. Really, in a way it was a relief, and we proceeded to get blood work, MRIs and an encephalopathy exam. It was there that I learned about an autism intervention program called Brilliant Minds in Destin, Florida, which practiced Behavior Analysis. We made an appointment for Lucia right away.”

At Brilliant Minds, Rachael and Karl met medical director Gina Balogne, with whom Mueller remains close friends. Rachael described Lucia at the time as being “either a little angel or horrid.” Balogne was soon able to teach Lucia to pronounce a “hard c” (a ‘mand’ for “candy”) and Rachael felt she was seeing a miracle.

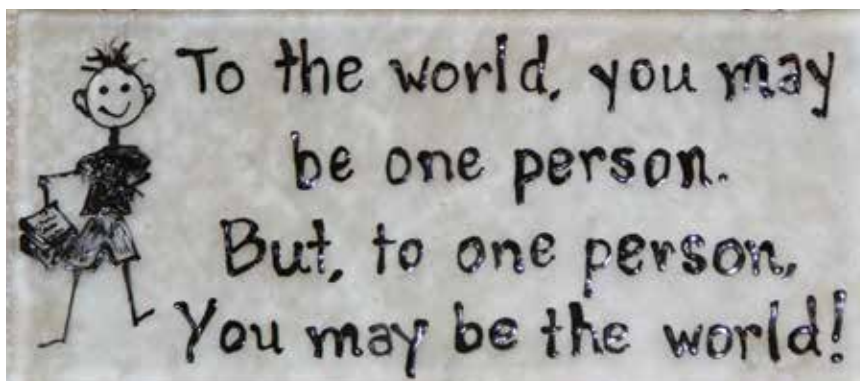
“Everything changed inside me when I saw her talk for the first time,” Mueller said. “On the way home I turned to Karl and said, ‘Honey, whatever it takes, Lucia is going to come here.’ It was as simple as that. Karl agreed.”

## A new way of living

From Elberta to Destin is a four-hour round trip. The sessions lasted three hours each, and were held three times a week. That meant the Muellers had to learn not only how to squeeze in 20-plus hours a week in their “spare time,” but they also had to figure out how to pay for the therapy.

“The coolest thing they did at Brilliant Minds was





to install closed circuit cameras so the parents could watch the therapy sessions," Mueller said. "As I watched Lucia's and the other children's progress, I at first became intrigued, and then I just fell in love with it. Why? Because *all* of the children made progress. Each one of them! Yes, there were different levels of response but you saw them all growing right before your eyes."

Mueller knew she needed more training, and returned once again to the University of South Alabama and completed her Masters in Elementary Education. She also received Board Certification in Behavior Analysis (BCBA) at the University of West Florida in Pensacola.

**"Each child, of course, is unique," Mueller said. "Basically, this whole scene is about individual students. The individual. You've heard the phrase 'If you've met one person with autism, you've met one person with autism.' Well, it's true. We keep careful program books, the child's whole history really. We are constantly updating what we do, constantly tracking mands."**

Meanwhile, in an effort to pay for Lucia's therapy, and to help other children struggling with the costs of attending Brilliant Minds, Karl and Rachael, with the help of many devoted friends, established a "FunRaiser" at Pirates Cove. The weekend long music celebration draws hundreds of people to the marina where they combine great times in a fun environment with autism education and awareness. The sixth annual "Illuminating Autism FunRaiser" was

held the first weekend in June and raised more than \$60,000. (*See related story on FunRaiser in this issue.*)

About this time, Rachael felt capable of opening her own school. The year was 2007.

### **New school, new opportunities**

"Here at High Hopes School it's me and three other teachers," Mueller explained. "We are very fortunate to be housed here at St. Benedicts. Our children are able to enjoy everything the school has to offer, such as field trips, classroom parties, and field days. Plus, the private school setting has much less red tape than trying to do this in

a public school setting. We feel like an old country day school, and have a strong feeling of protection here."

High Hopes has served a total of 13 families, and Mueller's vision is to eventually have a school of her own.

"I would like to have children with developmental delays in the classroom with their more typical peers, but use the principles of Behavior Analysis with all of the students," she said. "If

you applied these principles in a typical curriculum it would take care of all behavior issues, of which there are plenty, no matter who you are teaching! Here at St. Benedict's many of the younger grade teachers have implemented it with real success."

Mueller and her colleagues focus on language and social skills, using the iPad, Dynavox, and other speech and learning technologies.

### **Success stories**

"We are seeing amazing changes," she said. "For example, Conner here came to us when he was two years old, and he was a screamer. His parents had taught him two words – hammer and volcano – but all he really did was scream and hit and throw toys. We saw right away that Conner loved to climb so the first word we taught him was 'up.' We call them 'mands.' A mand is something you want – like, 'I talk, you give.' Using that technique, Conner flourished. His teacher in the future will need to do right, but Conner is getting ready to start Kindergarten. He is going to do fine."

Indeed, to observe Conner in a classroom is to see a charming, active, and loving child who works hard to have fun while also following the "rules of the road" established in the classroom.

"Each child, of course, is unique," Mueller said. "Basically, this whole scene is about individual students. The *individual*. You've heard the phrase 'If you've met one person with autism, you've met one person with autism.' Well, it's true. We keep careful program books, the child's whole history really. We are constantly updating what we do, constantly tracking mands."

"Look at my own daughter, Lucia. Before we started this journey she was quite literally screaming and banging her head on the table. She too has thrived in this environment as part of our school and as a member of our family."





But High Hopes tries to do more than just teach language. Socialization is a big part of what they do. There is much interaction with other kids from the school, and the teachers work closely with other members of the students' families to ensure that school principles are carried out at home. "It's one thing for our guys to go to lunch or run around on the playground," Mueller said. "But it's also important for them to be with outgoing typical peers as much as possible."

Mueller said the job is really a way of life.

"It's fulfilling. It's a lot of work on some days, but there are those special moments. Our biggest challenge is not the children. It's the money. We know that what we are doing really works. We see that it helps people. So we want to expand it, to share it with more families. These teachers are worth ten times what they make here. They are truly motivated. And motivation is the key."

# ABOUT BEHAVIOR ANALYSIS

The field of Behavior Analysis grew out of the scientific study of principles of learning and behavior. It has two main branches: experimental and applied behavior analysis. The experimental analysis of behavior (EAB) is the basic science of this field and has over many decades accumulated a substantial and well-respected body of research literature. This literature provides the scientific foundation for applied behavior analysis (ABA), which is both an applied science that develops methods of changing behavior and a profession that provides services to meet diverse behavioral needs. Briefly, professionals in applied behavior analysis engage in the specific and comprehensive use of principles of learning, including operant and respondent learning, in order to address behavioral needs of widely varying individuals in diverse settings. Examples of these applications include: building the skills and achievements of children in school settings; enhancing the development, abilities, and choices of children and adults with different kinds of disabilities; and augmenting the performance and satisfaction of employees in organizations and businesses.

Source: Behavior Analyst Certification Board  
([www.bacb.com](http://www.bacb.com))

# APPLIED BEHAVIOR ANALYSIS

## EDITOR'S NOTE

The following two stories are included to add an “academic component” that might help explain the principles and practices that are inherent in the work being done at High Hopes School. Applied Behavior Analysis can be incorporated into fields beyond education, such as management, and this short article better details the principles as they apply to working with students on the autism spectrum. Its companion article details a summer program in Auburn that more or less parallels the year-round efforts of the staff at High Hopes School in Elberta. Its purpose, as well, is to demonstrate how the ABA principles used so successfully in Elberta can benefit students in different locations and applications. Thanks to Dr. Doris Hill and Dr. Margaret Flores of Auburn University for providing these excellent elaborations on a most important approach to educating our young people in Alabama.

Applied behavior analysis (ABA) is the technology of behavior analysis; it provides teachers with the ability to develop interventions with practical benefit for individual students and society. The experimental analysis of behavior is the basic science and ABA is the technology used to develop interventions to improve behavior that is observable and measurable. This methodology is used to support persons with Autism Spectrum Disorder (ASD) and other developmental disabilities to teach new skills, reinforce previously acquired skills, generalize behavior across settings, reduce interfering behaviors, and modify or structure the learning environment before a behavior occurs (antecedent interventions) to reduce behaviors that interfere with learning in the classroom.

Assessments, focusing on what happens before (antecedents) and after (consequences) a behavior occurs, are conducted before interventions are developed in order to form a hypothesis regarding the function (or purpose) of a behavior (e.g., to attain or avoid attention, to avoid task demands, attain or avoid tangible items or sensations). They are also conducted during intervention to monitor progress and make adjustments. The effectiveness of

interventions is evaluated through data collection and graphed using single subject design methodology.

---

***This methodology is used to support persons with Autism Spectrum Disorder (ASD) and other developmental disabilities to teach new skills, reinforce previously acquired skills, generalize behavior across settings, reduce interfering behaviors, and modify or structure the learning environment before a behavior occurs (antecedent interventions) to reduce behaviors that interfere with learning in the classroom.***

---

Effective programs implementing ABA methodologies are characterized by early intervention, intense programming (five days a week), systematic instruction (direct instruction, incidental teaching, discrete trial teaching) in a one-to-one or small group setting, with

objectives that address social, communication, adaptive, recreation, cognitive and academic skills (National Research Council, 2001). Progress monitoring and a focus on generalizing skills in the natural environment, along with interaction with typically developing



Dr. Doris Hill



Dr. Margaret Flores

*continued on page 16*



# Collaboration Enhances ESY Services

The 2012 Summer Program for Students with Disabilities provides extended school year (ESY) services to elementary school students (age 3-12) with autism and other developmental disabilities from Auburn City, Lee County, and Chambers County, Alabama. Auburn University's Department of Special Education, Rehabilitation, and Counseling (SERC) collaborates with these three school systems each year. Auburn City Schools provides classroom space, a school nurse, and a school system teacher, all of which are critical components of the administration of the program. All of the school districts identify schools in need of ESY services and arrange for their transportation to the program. The students

who attend the program have developmental disabilities affecting academic learning, social interaction, behavior and communication.

During the summer program, Auburn University students will collect and analyze data related to student progress. They will also use emerging technological tools like the iPad 2 for communication and literacy-based learning. Several teachers are evaluating a direct instruction, computer-aided reading program for students with limited expressive communication skills, conducting research on written expression,

visual scripts, the Picture Exchange Communication System and other technology based interventions to include video modeling and story based approaches to teaching social skills.

Undergraduate and graduate Auburn University students in the SERC Department are the teachers in 9 classrooms providing services to almost 70 students. Under the direction of Dr. Margaret Flores, Associate Professor in the Department of Special Education, Rehabilitation, and Counseling department, and Dr. Doris Hill, Coordinator of Educational and Community Supports, Center for Disability Research and Service, pre-service teachers involved in the program apply the research and evidence-based practices learned within their university coursework, fulfilling their fieldwork requirements. Doctoral students within the department, Shaunita Strozier, Regina Kearley, and LaTonya Terry, also apply their knowledge of mentoring skills within the program as they supervise classroom teachers.

Dr. Hill and Dr. Flores collaborate with other department faculty in conducting research and mentoring doctoral students in their research practices. Current investigations include language acquisition, math, and reading. Collaborations beyond SERC include observations by general education early childhood education students from the Department of Curriculum and Instruction, as well as a doctoral student from Music Education. Volunteer graduate students from Troy University and Auburn University in Montgomery are also incorporated into the programming day.

*continued on page 16*

**Several teachers are evaluating a direct instruction, computer-aided reading program for students with limited expressive communication skills, conducting research on written expression, visual scripts, the Picture Exchange Communication System and other technology based interventions to include video modeling and story based approaches to teaching social skills.**



## Collaboration Enhances ESY Services

*continued from page 15*

The extended school year program employs practices outlined by the National Autism Center for students who are in jeopardy of regression or recoupment over the summer of much needed skills as determined by the IEP team. These services, provided at Richland Elementary School, provide a learning environment conducive to academic growth. Auburn University's pre-service teachers develop goals for each student based on an Individualized Education Plan (IEP), which includes components devoted to social skills, mathematics and language arts. There is a low teacher to student ratio (approximately three to one) and it is a highly structured, highly engaging, positive learning environment.



## APPLIED BEHAVIOR ANALYSIS

*continued from page 14*

peers who model the appropriate target behavior, are also important to success for students with ASD using ABA technologies. These interventions focus on developing important academic, cognitive, social, recreational, and functional independent living skills needed for success across all environments in the community of choice (e.g. home, school, work, leisure). It is an integrated and evidence-based approach to working with students with ASD and other developmental disabilities. Successful interventions based

on ABA result in behavior change that enhances individual quality of life.

Positive behavior interventions and supports (PBIS) is another important part of any school-wide program. PBIS is a proactive approach to school-wide discipline and of benefit to all students, not only students with disabilities. Through PBIS, the behaviors that students are expected to demonstrate are operationally defined and then explicitly taught. Subsequently, students are recognized in a positive way for engaging in the appropriate behav-

iors. Students are taught behaviors in a context-specific manner. That is, if students need to learn the appropriate way to travel through the halls, then the teacher will teach, model, and allow the students to practice in the hall. Attention is focused on supporting students on three levels: primary (school-wide), secondary (classroom), and tertiary (individual). Supporting children in this way improves the likelihood that they will engage in behavior that is effective, efficient, relevant, functional, and socially appropriate.



# *In their own words—*

Teaching is a passion at  
**HIGH HOPES SCHOOL**

## **LAURI TURNER**

I'm a behavior therapist working on my Masters in Exceptional Education as well as my BCBA certification. I was a teacher before I moved here and I was Rachael's first hire. I really enjoy the freedom we have at High Hopes and thrive on the one-on-one teaching opportunities that is central to what we do here.



## **LAUREN RUSSELL**

I'm a behavior therapist with a degree in Psychology. I, too, am working on my BCBA certification. I am sometimes the 'bad guy' but I just love working with all the children, especially Lucia. She and I have become very close. What we do here makes the children want to do their best. It's great to be a part of this team.



## **DANI WIGGLY**

After nine years in Albertville and three years in Arab, my husband became the head basketball coach at Gulf Shores High School. I tell Rachael that everything that has happened in my life has prepared me for work here at High Hopes School. I was an inclusion teacher and I worked with special families in North Alabama, so this is perfect for me. I knew the school side of things but here I am seeing the collaborative side that is such a big part of High Hopes.





Council Member Profile

## Scott Sligh 'doesn't look back'

ACDD Council member Scott H. Sligh, Professional Engineer, is the Electric Superintendent for the City of Fairhope, Alabama.

Born in Opelika but raised in various places while his father worked as an engineer for Reynolds Metal, Sligh spent time in Little Rock, Baton Rouge, Corpus Christi, Indiana – and even Australia.

"We moved around a lot and about all I wanted to do was to fish and play baseball," Sligh recalled. "I didn't want to go to the prom or any of that kind of stuff. I wanted to fish. My mom says I could fish before I could talk.

She even has a photo of me at age 16 in Australia standing next to an 18-foot Great White Shark. Fishing and the coast has always been a part of

***"My mom says I could fish before I could talk. She even has a photo of me at age 16 in Australia standing next to an 18-foot Great White Shark. Fishing and the coast has always been a part of my life. I'm sure that's part of what brought us to Fairhope."***

my life. I'm sure that's part of what brought us to Fairhope."

Sligh said that growing up that he was "belligerent" and kind of a bully. His parents wanted



***"I was so excited," he said. "I had always wanted a son that I could take hunting and fishing. When I realized that Nathan had been born with Down Syndrome I was devastated. I barely spoke for the next two days. Andi got one of her Catholic priests to come in and talk to me and, it's hard to explain, but something changed. I just got up and announced that I was going to work. I always tell my guys that you can't change what happens to you, you can only choose how you respond. I felt then that I needed to walk the talk. And from that day forward I haven't looked back."***

him to get an education so he reacted by leaving home and coming to Alabama, but he wound up as a student at Auburn. In spite of this self-described "belligerence," Sligh graduated as the top engineering student in the entire university. He also married a fellow Auburn engineer, his wife of 16 years, Andi.

"She and I met at a job interview with Southern Company," Sligh said. "There were ten of us going for three jobs, and she and I both got hired. They put Andi into an energy trading group. It was very intense, but when we had our children she walked away and has never looked back. She found something much more important to do."

After a stint in Decatur with Alabama Power, Sligh was recruited to Fairhope, where he has lived ever since with Andi and their two children, Sarah Kate and Nathan.

"Sarah Kate is nine years old," he said. "She was born ten weeks early

with Cerebral Palsy and did not walk a step until she was three. But a selective dorsal rhizotomy procedure allowed her to walk. After six weeks of intensive physical therapy in Birmingham, she started a long effort to do everything she could within her limitations. She is a born fighter. I can tell you that if Sarah Kate was a 20-year-old male, she would be a Navy SEAL sniper. She has unbelievable determination."

Sligh's daughter is on the swim team and plays recreational softball.

"She is the slowest person by far in both sports but she loves it," Sligh said. "And the support she gets from her teammates is inspirational. Andi said seeing how her teammates support Sarah Kate gives her hope for the future."

On Sligh's 40<sup>th</sup> birthday his son Nathan was born.

"I was so excited," he said. "I had always wanted a son that I could take hunting and fishing. When I realized that Nathan had been born with Down Syndrome I was devastated. I barely spoke for the next two days. Andi got one of her Catholic priests to come in and talk to me and, it's hard to explain, but something changed. I just got up and announced that I was going to work. I always tell my guys that you can't change what happens to you, you can only choose how you respond. I felt then that I needed to walk the talk. And from that day forward I haven't looked back."

Sligh's devotion to his electrical linemen on the job was recently displayed in a passionate "Letter to the Editor" of a national trade magazine, wherein he demonstrated the often-overlooked bravery and heroism of power linemen, calling them real-life, modern-day cowboys. Sligh said that he has been blessed with "a good career and big shoulders," and that he now has a larger mission in life.

"As I said, I was something of a bully growing up," he said. "That's in the past. We now feel like it's our job to take

up for people who cannot take up for themselves. We do this any way we can – Special Olympics, Buddy Walk, whatever. And being part of the Council is a great way to network, a great place to learn. The more you experience the more you know. We have seen Sarah Kate grow into a strong person. With Nathan we are just awaiting developmental delays and we're ready to grow in any way we need to grow. Right now he has learned a lot of sign language. And he loves to imitate our dogs!"

Sligh's passion is recreation. His office walls are covered with game fish and waterfowl. He explores the back waters of the Tensaw Delta, and has an abiding passion for Alabama's ancient Native American cultures.

"I have been logging in as many hours as I can to work toward my captain's license," Sligh said. "My vision is to someday become a boat captain and take children with a variety of special needs out to explore and fish in the Gulf and the bay. I think about it all the time and have some great ideas. That's a vision that I am determined to see come true. And just know this. If I say I am going to do it you'd better get on board or get out of the way."



# Sligh's wife is known to thousands as 'Andi the Blogger'



Although she herself was a brilliant and very successful engineer and energy trader, Andi Sligh has found a higher calling. With a rare and contagious passion, she is raising her two children with disabilities. Both she and Scott do everything in their power to build capacity for Sarah Kate and Nathan. And since January of 2008 they have shared those successes and challenges with the world through Andi's warm, bold and sometimes controversial blog—[www.bringingthesunshine.com](http://www.bringingthesunshine.com).

"The blog is funny," said Scott. "It's touching. Sometimes she writes things that bring a variety of reactions. She often shows how people everywhere have a capacity for goodness, such as someone she runs into at the beach, or how wonderful Sarah Kate's softball and swim buddies are. It's kind of an

electronic diary of our lives together, I guess you could say, complemented by Andi's excellent photography. I'd say the theme of the blog is that we are all more alike than we are different."

With four posts a week, Andi has fans around the country. She receives responses from people across the ethnic, social and geographical spectrums, and hears from people with all kinds of viewpoints. It's almost impossible to relay the "vibe" the blog generates – it's much better to see it for yourself.

Here is an excerpt:

## **This is Andi's intro...**

Welcome! My name is Andi. I'm an ordinary mom with extraordinary kids, living an ordinary yet extraordinary life. Join me as I navigate the waters of life with a daughter with cerebral palsy, a son with Down syndrome, an adventurous husband, a wild Westie, a rescued Schnoodle, a camera, and a worn out pair of running shoes.

I started this blog as a way to work through my personal feelings about my life and how different it feels to me from what I had planned or expected. I made it public so that my family and friends could read it, and have been amazed at the positive reception it has received from family, friends, and strangers alike. Some people have told

me simply that they enjoy my writing, while others have praised me for the work that I am doing.

Work. That I'm Doing.

So I continue to write. There are times when I write from a dark place in my soul, and at other times I write with laughter in my heart. Sometimes I share my opinion on weighty topics, and other times I dwell on minutiae. Sometimes I don't write at all, and post an image or link that means something to me. What I always strive for, though, is for every post to be Real.



My family is more like most families than we are different. My children are more like their peers than they are different. Yes, we do have special challenges, but with every

challenge faced by having a child with special needs, there is an equal blessing to be experienced. I look forward to the years of blessings to come and to sharing them through this blog.

"...She often shows how people everywhere have a capacity for goodness, such as someone she runs into at the beach, or how wonderful Sarah Kate's softball and swim buddies are. It's kind of an electronic diary of our lives together, I guess you could say, complemented by Andi's excellent photography. I'd say the theme of the blog is that we are all more alike than we are different."





**And here is one of (literally) hundreds of posts, this one from just a few weeks ago...**

One of the best things about living near the coast is that we can head to the beach for the day without the need for reservations.

We did just that on Saturday and again on Monday, loading down the family wagon with towels, sunscreen, and various other beach accoutre-

**“If there is anything at all special about me, it is because my child made me that way.”**

ments. We parked at a semi-secluded public beach away from the high-rise condos and souvenir shops and enjoyed the day. Because of its location, most of the people at this particular beach are either locals or at least regulars. There are no chair rentals, no beach bars, and no swimming pools.

It's our kind of place.

Upon arriving, I spotted a family just a little ways down from us. One young woman in the group stood out

right away. Though I couldn't see her face, I was fairly certain from her body shape and the body language of the people standing with her at the water's edge that she had Down syndrome. I scooped up Nathan – the equivalent of a Golden Ticket into this exclusive club – and headed over to introduce myself. She and her family were warm and friendly, and we chatted for several minutes.

We stayed for several hours and the kids played – Sarah Kate alternating between sand creations and marine life imitations, while Nathan squealed at the waves and threw sand by the handfuls into the air. On a busier beach, it's unlikely that many people would have noticed anything different about him at all, and though walking in the deep sand is a struggle for Sarah Kate, she is like a fish in the water.

It was easy to forget that we are “different.”

Later in the afternoon, as we were gathering our things to go, a lady who'd been sitting near us all day spoke to me. The only pleasantries we'd ex-

changed in the previous six hours were a passing comment on the book she was reading, so when I saw her looking intently at me, it gave me pause.

*“I really admire you and your husband. I have a family member with Down syndrome and it takes a very special person...”*

I was torn. Ever since Sarah Kate was a baby, I've wished that people would just Say Something rather than looking at my kids and wondering. But on the other hand, I don't really want to hear that people think I'm special just because I parent two special kids.

We all have a desire to be admired and to feel special, of course, but from that adjective necessarily follows the sentiment that not everyone can do what I do. I don't want that to be the case – I want every parent (and potential parent) to embrace the idea of doing the extraordinary, so that the extraordinary becomes ordinary. I gave her what I hoped was a warm and genuine smile, and told her,

*“If there is anything at all special about me, it is because my child made me that way.”*



*Personal journey led to professional passion--*

## **Campbell grows from street-gang social work to distinguished disability researcher**

Growing up in the 1960s watching his father work as a crane operator on Detroit high-rises, Dennis Campbell spent his share

Chicago where he began doing what he has done every day ever since: trying to help people who needed help.

***Campbell took his knowledge to Chicago where he began doing what he has done every day ever since: trying to help people who needed help.***

of time working on farms near his home in Sterling Heights. After a couple of years of undergraduate study at Michigan State University, Campbell became involved with a volunteer group helping families in the area. Soon thereafter, he took his knowledge to

“In Chicago I worked with uptown street gangs in the Lawrence and Kenmore areas,” he said. “The work was sponsored by the Catholic Church. I actually worked out of a storefront that was once a bar that was owned by Al Capone. I stayed in that kind of work for a while, though there were different areas of focus. I also spent time at a non-profit day labor camp trying to find work for recovering alcoholics.”





***“One of the most fascinating things to me at that time was that seven people we polled identified themselves as having autism, and also as making over \$150,000 annually. What that told me was that when people with autism get their brains to focus in the right way they can do amazing things!”***

Looking for a change, Campbell decided to move to the South and ended up in Auburn doing construction work.

“About 1975 I began working with the Lee County Youth Development Center,” Campbell said. “I did that actually for six or eight years and really learned a lot about young people and their troubles, as well as about myself.”

In the early 1980s, Campbell met Shari Huffman the woman who would a few years later become his wife.

“Shari suggested that I go back to school,” Campbell recalled. “I got into Auburn’s Social Work program and with the economy being in recession I stayed on and got my undergrad and Master’s degrees in Sociology. I was also working with the Lee County AIDS Outreach when Shari and I finally got married. Our daughter Amy was born the next year at East Alabama Medical Center. She was immediately transported by neonatal ambulance to Montgomery where Dr. Narula told us that he had diagnosed Amy with Cri du Chat Syndrome, a rare, low-incidence chromosomal disability that is seen in

about one out of every 35,000 people.”  
(See related story on *Cri du Chat* in this issue.)

### **A change in professional focus**

“Soon after that, based on our new family experience, Nancy McDaniel at Auburn invited me to join the Inter-agency Coordinating Council for Early Intervention,” Campbell said. “I was able to help with the financial planning of the program and got a little administrative experience in the area of disabilities and working with families. Then, I started my long and very fruitful affiliation with the DD Council in Individual and Family Supports. I applied for a regional position but eventually became the State Coordinator. This was in 1994.”

Overseeing five regional councils, Campbell said this was a truly great project.

“We built wheelchair ramps, bought washers and dryers, and really just did all kinds of stuff that made life easier for families who had a child with a disability. These things would not

have come from anywhere else if not for us. As a young father in a similar situation, of course, I understood very much what these families were going through.”

Back at Auburn University, Dr. Samera Baird had a grant to help someone work toward a Doctorate in Special Education. Baird called Campbell and he said yes.

### **Back to school, back to the ACDD**

“So all of a sudden I found myself as a full-time Doctoral student in Rehabilitation and Special Ed,” Campbell said. “I focused on Early Childhood Special Education. Our daughter Amy enrolled in Auburn’s Project AIM, an early intervention program, and soon thereafter our second daughter Kelly was born. I can tell you that Dr. Baird, Dr. Reilly and the folks at Auburn and Project AIM were a huge help and motivation in our lives then and now.”

As he completed his dissertation, Campbell was offered a job at Arkansas State University in Jonesboro. Campbell thrived at Arkansas State. His research focused on low-incidence disabilities with a special interest in Cri du Chat Syndrome. In spite of the good program at ASU, Campbell in 2005 took a job at the University of South Alabama in Mobile.

“About this time, the ACDD put a lot of money into studying autism in the state of Alabama. South Alabama had its polling center so I put the two concepts together and conducted a most interesting and revealing statewide poll. One of the most fascinating things to me at that time was that seven people we polled identified themselves as having autism, and also as making over \$150,000 annually. What that told me was that when people with autism get their brains to focus in the right way they can do amazing things!”

A separate DD Council grant led Campbell to work with families who had a child with autism. Part of the grant involved developing a secondary

***“The original DD Council grant provided the groundwork to prove that we really had something going,” Campbell said. “Without something concrete to show, we wouldn’t have been able to win the grant. Myra was instrumental in setting up the research and advising us. We also got a lot of help and support from John Houston (ADMH), Dr. Mabrey Whetstone (ALSDE), and Dr. Cary Boswell (ADRS), as well as from local schools and agencies. The support from these state and local agencies did a lot to help us really impress the grant people at the federal level.”***

transition model called Project CHOICES that helped middle school and high school students navigate the system. With three other faculty members from USA – Dave Ellis, Abbie Baxter, and Harold Pardue – this led to developing a database on transition and the IEP process.

### **ACDD program leads to federal grant**

“We were able to translate that ACDD grant into an Institute for Educational Sciences federal grant from the Department of Education,” Campbell said. “That \$1.3 million three-year grant is ongoing as we speak. The database is designed for parents to be the gatekeepers. The family is a part of the larger community, and if you provide the family with good information about what’s out there, they will make good choices. It’s a systems change grant. We have a partner in our School of Computing here at USA working on this. We’ve even expanded it to make it like a TRON-style animated video game format for the students.”

When the parents, students and teachers all answer the same basic questions the data system develops a report that shows ‘quick and easy’ points of agreement and disagreement and a picture of what the student wants to do when he or she leaves high school. As a result, this helps students and their parents frame meaningful questions for their IEPs.

The other side of the database is a community linkage that uses the students’ abilities to provide suggestions of local agencies that may be able to assist.

“It’s a Person-centered planning model,” Campbell said. “It at least gets young people and their families and teachers thinking more clearly and easily about these important issues in the student’s life.”

Campbell remains grateful to the ACDD and its Executive Director, Myra Jones, for laying the groundwork that led to this huge federal grant.

“The original DD Council grant provided the groundwork to prove that we really had something going,” Campbell said. “Without something concrete to show, we wouldn’t have been able to win the grant. Myra was instrumental in setting up the research and advising us. We also got a lot of help and support from John Houston (ADMH), Dr. Mabrey Whetstone (ALSDE), and Dr. Cary Boswell (ADRS), as well as from local schools and agencies. The support from these state and local agencies did a lot to help us really impress the grant people at the federal level.”

“As it is being tested now, it turns out it will help families with children who have disabilities, and it will do a lot to help our state. Mobile is a perfect place for this kind of study because there are so many more kids in the school system with disabilities. The development just would not have worked as well somewhere else.”

Campbell and the USA team are working on a grant now to extend this research as an efficacy study to see if

the data system works as well in school systems across the state.

“We want to perform a randomized control study and make it become an evidence-based practice,” he said. “Our department here at South Alabama is small, but we do very good work in early intervention, autism and developmental disabilities.”

“In my own research in low-incidence disabilities, especially in Cri du Chat, we’ve got full evaluations on 100 young people,” he said. “This is the second biggest database of evaluations in the world, and the biggest in the country. Connecting the grant results to my own research, I want to provide customized career development based on the student’s abilities. And we’re trying to streamline the reporting requirements for teachers. As we get more and better information to the IEP team it will make teachers’ jobs easier. If the job for the teacher is not easier, they just won’t do it.”

“I never thought I would be here, doing this kind of research, working with these families. But you just never know where the road of life is going to lead you. My own journey started at home with Amy, but it has led me to work with some great families and some wonderful colleagues here at South Alabama. And without the support of the DD Council, I’m not sure any of this would have ever happened.”

***“I never thought I would be here, doing this kind of research, working with these families. But you just never know where the road of life is going to lead you. My own journey started at home with Amy, but it has led me to work with some great families and some wonderful colleagues here at South Alabama. And without the support of the DD Council, I’m not sure any of this would have ever happened.”***



# Cri-du-chat Syndrome

## A Topical Overview

*The following is a heavily condensed and edited version of an academic paper written by Campbell and professional colleagues Mary Ester Carlin, Joseph E. Justen III and Samera M. Baird. It originally appeared in on the Five P Minus website, Copyright 2004 5p Minus Society*

*Cri-du-chat syndrome* (CDCS) refers to a unique combination of physical and mental characteristics associated with a loss of genetic material on the distal short arm of the fifth chromosome. Also called 5p- syndrome, 5p monosomy, or Cat Cry syndrome, it was first identified by Dr. Jerome Lejeune in 1963, and so named because of the distinctive cry in infancy that resembles the meowing of a cat.

The term *Classic Cri-du-chat syndrome* has sometimes been used in describing individuals with the more common features described above and a deletion involving a specific region located at chromosome 5p15.2. However, many individuals with CDCS show deletions that involve more than the 5p 15.2 region or other 5p genetic material (DNA) and may demonstrate additional or other clinical symptoms.

Most young children with CDCS continue to demonstrate low muscle tone, increased extension, and at least some degree of instability at many joints. As they mature they may develop hypertonia or increased muscle tone. Other physiological manifestations may include limited range of motion in some joints, excessive drooling, feeding problems, hypersensitive hearing, tactile defensiveness, nearsightedness, and under development of the optic nerve. Differences in dental occlusion have also been reported which can cause an overbite later in life if not corrected.

Individuals with CDCS often had some form of hearing loss, and cardiac complications are common with about 30% having heart malformations. In addition, an early onset or delayed puberty in females was also reported. Disorders of sleep, feeding problems, constipation (increases with age), infections, and behavior problems are fairly common.

Other medical problems that are sometimes associated with the CDCS include:

- low birth weight,
- cleft lip and palate
- respiratory complications including susceptibility to pneumonia,
- gastrointestinal structural differences such as intestinal malrotation,
- gastroesophageal reflux,
- susceptibility to middle ear fluid and infections,
- susceptibility to other infections,
- curvature of the spine (scoliosis),
- inguinal and abdominal hernias,
- orthopedic structural differences,
- slow growth rate,
- differences in various organ systems
- laryngeal structural differences,
- colic, jaundice,
- susceptibility to dehydration,
- kidney and urinary tract problems,
- abnormal urethral opening in male.



CDCS is a relatively uncommon syndrome with an incidence rate of between one in 15,000 live births and one in 50,000. actual incidence in the population is probably somewhere between these two figures. Most geneticists currently accept a figure of one in 35,000.

Prior to the 1980s, research on CDCS consisted primarily of medical studies of individuals who had lived in institutions. Most of these individuals did not have access to a loving family environment, education, or systematic medical care. Consequently, the prognosis for individuals with

CDCS reported in early studies was very pessimistic. Parents of children diagnosed early with significant disabilities in the United States were strongly encouraged to place them in institutions and forget them. This was certainly true for individuals with CDCS. Current research on CDCS presents a more optimistic prognosis. When children

***Consequently, the prognosis for individuals with CDCS reported in early studies was very pessimistic. Parents of children diagnosed early with significant disabilities in the United States were strongly encouraged to place them in institutions and forget them. This was certainly true for individuals with CDCS. Current research on CDCS presents a more optimistic prognosis. When children are provided a positive home environment and access to early intervention programs a more favorable prognosis is expected.***

are provided a positive home environment and access to early intervention programs a more favorable prognosis is expected.

Children with CDCS usually receive primary medical care from a pediatrician, although other specialists routinely involved may include an ear, nose, and throat specialist (ENT), an eye specialist (ophthalmologist), a bone specialist (orthopedist), a dentist, and a geneticist. As mentioned earlier in the paper there are many medical or health problems associated with CDCS. Hospitalization for the treatment of respiratory infections and placement of ear tubes is not uncommon. These health problems notwithstanding, many researchers reported individuals with CDCS tend to be relatively healthy. Only 30 percent experience chronic illness requiring over six medical visits per year, and 56 percent were considered generally healthy requiring only

two to six doctor visits per year. Early reports of significant numbers of deaths in the first year of life are not supported and life expectancy for individuals with this syndrome has been increasing. With routine medical care, individuals with CDCS can be expected to survive into adulthood with many reaching middle age and beyond.

The information that exists in the medical literature continues to report individuals with CDCS as having very little language, poor cognitive performance, neurological and motor problems, as well as a variety of problematic behaviors. While all of these issues still exist, the research also describes these individuals as happy, friendly, and capable of learning.

Because of low incidence, little information concerning CDCS exists in the educational literature. Very little systematic research provides insight into educational strategies for individuals with CDCS. In a recent study by Campbell (2002), data from 143 individuals with CDCS was analyzed. On the average, these individuals walked holding hands a year later than typically developing individuals (range:



10 months to 144 months; mean 24 months) and walked independently seven months later (range: 16 months to 144 months; mean 31 months. They rolled over (range: 3 weeks to 36 months; mean 6 months), self-fed using utensils (range: 2.5 months to 108 months; mean 21 months),





and drank using a cup (range: 6 months to 120 months; mean 21 months) within the typical age of development. Children who received early education met milestones earlier than those

who had not. They averaged rolling over two and one half months earlier, sitting independently eight months earlier, and walking nine months earlier than those in the study without the benefit of early educational interventions.

In the area of communication children in the study required an extra seven months to use gestures to communicate compared to typically developing children. They were on the average 34 months of age when they used their first

***Many of the issues faced by families, like developing functional communication and redirecting problem behaviors, are common. There appears to be a wide variation in the occurrence and severity of problem behaviors from one individual to another. Children served in more inclusive educational environments appear to have a more socially appropriate behavioral pattern. Early education has been shown to help these children reach developmental milestones earlier. Communication interventions should begin in infancy.***

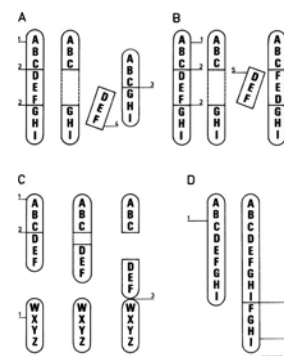
sign (range: 6 months to 144 months), 48 months for multiple signs (range: 12 months to 168 months), and 45 months when they spoke several words (range: 12 months to 120 months). Those individuals who received early education used gestures 20 months earlier, first signed eight months earlier, used multiple signs ten months earlier, and multiple words 12 months earlier than those who had not received early education. The focus on functional communication provided in most early education programs would certainly be a probable contributing factor to this difference.

Practitioners should recognize that individuals with CDCS have the capacity to learn. Earlier research significantly underestimated the ability of these individuals. Parents should be encouraged to participate in their children's therapies and never to underestimate their ability.

Having observed hundreds of children with CDCS, the authors feel we can draw several general conclusions. Younger children who have had early intervention seem

to have better communication abilities than older individuals without the benefit of these programs. Self-stimulating behaviors, which can be a manifestation of frustration or boredom, seem to be present from a very early age for some children. Practitioners should target behaviors early and consistently.

Many of the issues faced by families, like developing functional communication and redirecting problem behaviors are common. There appears to be a wide variation in the occurrence and severity of problem behaviors, from one individual to another. Children served in more inclusive educational environments appear to have a more socially appropriate behavioral pattern. Early education has been shown to help these children reach developmental milestones earlier. Communication interventions should begin in infancy. Sign language should be taught and encouraged along with other total communication methods including picture exchange symbols, augmentative communication, and spoken words. Receptive language skills surpass expressive skills, thus interventions should be targeted at the child's receptive developmental level rather than the expressive. Generally speaking, research findings suggest that effective educational strategies based on empirically based methods likely to maximize the potential gain for children with significant disabilities also work well for children with CDCS. Above all, children with CDCS can learn and the quality of their life is much improved in a home situation with early intervention.



***Generally speaking, research findings suggest that effective educational strategies based on empirically based methods likely to maximize the potential gain for children with significant disabilities also work well for children with CDCS. Above all, children with CDCS can learn and the quality of their life is much improved in a home situation with early intervention.***

ACDD Council Member—

# Greene wins

## Deane Corliss Exemplary Teaching Artist Award

ACDD Council Member Carolyn Greene, a long-time art teacher with VSA Alabama, has been named as the first-ever recipient of the Deane Corliss Exemplary Teaching Artist Award. Greene, through VSA, teaches a monthly art class to people with disabilities at Mobile's Independent Living Center. In addition Greene teaches art three days per week at the Mobile ARC. The Mobile ARC classes began in 2001 through a VSA grant making Greene the longest tenured teaching artist with VSA.

The award is named for Deane Corliss, a much-loved VSA Board Member who supported the arts for people with disabilities through VSA programming in Alabama.

Greene also participates in the annual ArtPartners on the Bay where people with disabilities are partnered with community artists creating works of art that are auctioned at an exciting event held at the Eastern Shore Art Center in Fairhope. ArtPartners on the Bay raises funds for VSA Alabama to

has so much fun and some long lasting relationships have been established between community and "emerging" artists—and that's exactly what we want!" Greene said.

Greene knows that art is a wonderful way for all people to express themselves. Wonderfully, too, people with disabilities often do not have the inhibitions about their work that our typical population has, Greene believes. Many create quickly and with little deliberation.

That approach produces a very fun, fresh, "primitive" style art that can work well into any collection. Some art work by people with disabilities really can be seen as Outsider Art.

"In the typical population one knows if he or she is an artist," she said, "but there is a difference for a person with a disability. I believe that if they can just hold a brush they can become

an artist. It may take a lot of help or a little, or no assistance at all. But to me, everyone is an artist."

"The object of creating art in this unique setting is *joy*," she said. "The object is *fun*. I have here with me today two beautiful examples of art from the



Independent Living Center of Mobile's VSA art class -- one by Sonya Williams and the other by David Witt. I am taking both paintings to Birmingham to be a part of the VSA Creativity Show to be held in April. With Sonya I typically sketch the image and she applies the paint and selects the colors. David, who is 70 years old, painted this beautiful tea cup because he still enjoys a cup of tea with his mother whom he visits on weekends."

Greene said her unique career as an art teacher has been beyond rewarding.

"I am so blessed to have had the opportunity to work with these wonderful people and help them discover that they are artists."

Congratulations Carolyn on receiving this award!

***"When we paint for ArtPartners I invite my artist friends to partner with a person with a disability. Everyone has so much fun and some long lasting relationships have been established between community and "emerging" artists—and that's exactly what we want!" Greene said.***

support art programs for people with disabilities in Mobile and Baldwin Counties (*see related ArtPartners stories in Fall 2011 issue*).

"When we paint for ArtPartners I invite my artist friends to partner with a person with a disability. Everyone



# Jessika Burton's tissue dolls

*reflect nurturing of mentors,  
her own innate creativity and  
love of fashion!*



Jessika Sikay Burton was born in Doraville, Ga., on August 14, 1990, to my daughter Valerie Y. Graham and Jeffrey Burton. She was a beautiful baby, though it soon became apparent that she was not reaching the same developmental milestones as other children her age.

By the time Jessika was three years old, her basic developmental skills – such as verbal communication, tactile expressions, social play and familial interactions – were decidedly introverted. Because she was non-responsive to outside stimuli, Jessika's mother sought professional medical and psychological help. Following extensive testing and evaluation, these medical professionals determined that Jessika had a diagnosis of autism. Her mother was undaunted and determined to provide Jessika with the resources she needed to succeed.

When Jessika began Hightower Elementary at age six, she surprised her family by doing well in the computer class she was placed in. However, she still spoke very little, pointing at what she wanted or speaking in monosyllables. Jessika was still in this phase when she was faced with an unspeakable tragedy – her mother's sudden, unexpected death. We could only imagine the hurt she felt, but all she did was smile. I think it's because she was remembering her mother's smile, but she had no way to tell us that.

At this point in her life, Jessika's uncle (and my son) Charles and I took Jessika and her father into our home with us in Mobile. Although Jessika's father Charles eventually moved out on his own, Jessika remained in a very stable environment with plenty of help from her father. She was never really a problem, and at this point she began entertaining herself by making tissue paper dolls, as she and I continued to grow closer and closer.

Jessika enrolled at Crichton/Spencer Elementary, Scarborough/Causey Middle Schools, and finally graduated from Baker High School in 2008 with a certificate of completion. Her teachers enjoyed her, as she had no behavior issues, and she had good social exchange with them as well. Jessika had even begun to communicate with her peers.

Because of this nurturing from both her teachers and family mentors, Jessika reached another great milestone in her life: she achieved a great weight loss. She went from wearing a 3X dress size to a size 14 in just two years. This was achieved through help from many people, including her doctor, the school cafeteria managers, teacher and family members. She also adhered to strict self-discipline in her eating habits. To

this day Jessika still wears a 14 dress size.

Most importantly, Jessika has kept up and improved her self-taught art skills as a doll maker. Influenced more by outside exposure, Jessika's dolls are made of more materials and have become more detailed. Maybe these ideas come from browsing fashion magazines, or her involvement in church and social events, traveling, and participating in recreational activities such as camp, all of which probably fire her imagination.

As a result of school and Vocational Rehabilitation counseling, Jessika and I selected the Mobile ARC as a starting point after her graduation and we are both very pleased with her progress. Her program is called Transition From School To Work and it has benefited Jessika immensely. She is surrounded by service coordinators, co-workers and friends. We feel very blessed to see how far she has come, and we hope some of you are able to see and enjoy the beautiful dolls she continues to make, as the power of art lifts Jessika higher and higher.

*For more information on the Mobile ARC's art programs, or to learn more about Jessika's dolls, email art teacher and ACDD council member Carolyn Greene at [carolyndgreene@yahoo.com](mailto:carolyndgreene@yahoo.com).*



**Alabama Council for Developmental Disabilities**

RSA Union Building  
100 North Union Street  
P.O. Box 301410  
Montgomery, AL 36130-1410

PR SRT STD  
U.S. Postage  
**PAID**  
Montgomery, AL  
Permit #456

**Read all our past publications  
at our website**



**Visit us at [www.acdd.org](http://www.acdd.org)**

