



## Claiming your holiday cheer

by Shannon Gonsalves  
reprinted with permission from  
Complex Child E-Magazine

For many people, the thought of the holidays approaching provides another source of anxiety. This can be especially true for families with children who have complex needs. How will my child handle the chaos of a family gathering? Will he eat some of the holiday dinner? Please, God, let him have one day without pain. Will I be able to find a toy that will be appropriate and work for my child's needs? How can I afford my child's medical bills and presents, too?

These thoughts, questions, and prayers are common ones for families with children who have complex needs. It adds another layer of difficulty to an already stressful time of the year. Sometimes, just watching other kids who are typically developing can be a bitter pill to swallow.

Can anything be done? Some of this stress can't be avoided, but how we handle it can make a huge difference in how much enjoyment we get out of the holidays.

### Set Realistic Goals

Every year, I hope that my son will partake in the family meals lovingly prepared on Thanksgiving and Christmas days. However, most years, I am disappointed. For the first few years, I let my



*The holidays can cause anxiety if you allow it, but focus only on what is truly important and ignore what isn't*

disappointment of his lack of interest in these special meals overshadow my joy for the precious time that I was spending with our family. I still found enjoyment, but disappointment lingered in the back of my mind like a dark rain cloud looming over a beach party.

Last year, I decided to just accept that he probably wasn't going to eat dinner and, depending on how he greeted mealtime, I might not be enjoying yet another family meal. I set up his tube feeding supplies ahead of time, so I could casually get him going on his feed if he didn't eat. When it was time, I just did it as if it were any other meal. I sat next to him to keep him as entertained as possible. When he was clearly done, I excused him from the table to play instead of both of us leaving the room.

My goals have changed from worrying about

whether he'll eat or not to instead helping him find enjoyment in the time we're spending together. It has to be just another meal for us. It can't have that much significance that I let it ruin the time with family. If that means playing in his food, playing with toys, talking with family or even eating, so be it.

Decide what goals are really important for you to find enjoyment in your celebrations and don't set them too high. Oftentimes, our kids develop at different rates and we celebrate their "inchstones" instead of milestones. The same can be true for holidays as well. Keep your holiday hopes and goals to inches instead of miles, and let your family know why your child might not be treated the same as others.

### Recognizing Limits for You and Your Child

I know that my son doesn't do well in busy, crowded, loud situations. For this reason, I avoid going to our church's harvest party each year. We can have just as much fun dressing up at home and sitting in Nana's living room watching all the costumed kids come to the door.

If you know that your child just won't respond well to a situation, don't go. I know it gets harder when there are siblings involved. We've gotten around our daughter being disappointed by being willing to divide up and go in different directions. I might take my daughter to a party while dad does something fun with my son. When we went to a water park recently, my son stayed in the room while I took my daughter to the story hour. We

*Please see Holiday, Page 6*

### Inside:

- |   |   |                       |    |
|---|---|-----------------------|----|
| > Project SEARCH builds employment skills | 3 | > Family Voices       | 8  |
| > Military families and special education | 4 | > Book Review         | 9  |
| > Cool handy gadgets to help families     | 5 | > Let's YAC about it! | 10 |

**Editor:** Susan Colburn  
State Parent Consultant

**Layout and design:**  
Office of Communications  
and Information Staff

**Contributing writers:**  
Ree Clark  
Lisa Gibbert  
Sandra Hazzard  
Sharon Henderson  
Vonda Reeves  
Miracle Woods

**Address inquiries to:**  
Susan Colburn  
Children's Rehabilitation Service  
602 S. Lawrence St.  
Montgomery, AL 36104  
**Phone:** (800) 846-3697, (334) 293-7041  
**Fax:** (334) 293-7373  
**Email:** susan.colburn@rehab.alabama.gov

*Parent Connection* is a complimentary newsletter published by Children's Rehabilitation Service for families of children with special health care needs. The goal of this newsletter is to increase communication and share information about children with special health care needs and their families. The newsletter reflects a family-centered theme throughout and serves as a forum for family members to share information, thoughts, feelings, concerns, etc. Nothing printed or implied in this publication constitutes an endorsement by the Alabama Department of Rehabilitation Services.

This material is available in alternate formats upon request. Alternate formats include braille, large print or audio tape and may be obtained by calling the phone numbers listed above.

In the provision of services and employment practices, the Alabama Department of Rehabilitation Services does not discriminate on the basis of sex, creed, national origin, religion, race, age or disability.



## From the Director's Chair



Hello, Parents,

I hope that your children have gotten off to a great start this school year! CRS began its new fiscal year (FY 2015) Oct. 1, and we are pleased that we will be able to continue to provide you with the same quality services you received in FY 2014. We are continuing to work to improve our services each day.

You should be aware of the many changes in healthcare that will impact children with special health care needs in the coming years. CRS staff members are hopeful that these changes will bring about significant improvements in the lives of you and your families. The Lucille Packard Foundation for Children's Health funded a project to develop "Standards for Systems of Care Serving Children and Youth with Special Health Care Needs (CYSHCN)." These standards were published in March 2013. Since that time, CRS has been learning more about them and will be working to make sure that they are included in services provided to CYSHCN in our state. We want to make sure that any agencies or private practices providing services to your child are aware of the standards. We will share these standards and our progress with you through your local and State PAC (Parent Advisory Committee). If you need more information about your local PAC, please contact a CRS representative or ask about it at a CRS clinic.

Another change that I want to share more about in this newsletter is the Regional Care Organization or RCO. I decided to list some questions that you might have about RCOs and to answer them. I hope you'll read each one and if you have questions later, please tell your local parent consultant, CRS care coordinator, or other CRS worker, and we will be more than happy to try to find the answer for you.

### **Q. What is a Regional Care Organization or RCO?**

**A.** The cost of healthcare in Alabama has increased significantly due to complex health problems and chronic conditions. To help Medicaid solve the problem of increased costs, in 2013 and 2014 the Alabama Legislature passed a law to divide the state into geographic regions. The legislation requires that the regions be community-led, regional organizations. These Regional Care Organizations (RCOs) will coordinate the health care of Medicaid patients in each region and will bear the risk of contracting with the state of Alabama to provide that care. The Alabama Medicaid Agency met the first milestone by establishing districts effective Oct. 1, 2013.

### **Q. Will my child have to receive Medicaid services through a Regional Care Organization (RCO)?**

**A.** Yes. Your child will likely receive services directly through an RCO rather than through Medicaid. The target date for this change is Oct. 1, 2016; however, if a probationary RCO is up and running before then, your child's services may be provided by an RCO earlier.

### **Q. How will I know about this change?**

**A.** Medicaid will notify you of changes at least 90 days in advance. Medicaid also plans to educate you about the changes.

Please see Director, Page 9

## My daughter's 'SEARCH' for job skills, employment

by Lisa Gibbert, parent consultant

My daughter Brita gets up every morning, puts on her uniform, and hurries off to catch the bus with a big smile on her face. She's 19, has Down syndrome, and is in her last year of high school. But Brita isn't just going to school, she's also going to work, thanks to Project SEARCH!



*Brita Gibbert boards the school bus for classes at Thomas Hospital in Baldwin County as part of the Project SEARCH program, which provides job training and independent living skills*

### **Interning with Project SEARCH**

Brita is an intern at Thomas Hospital, Project SEARCH's host site in Baldwin County. Project SEARCH is a program for young adults with developmental disabilities that provides them with a unique opportunity to receive job skills training and independent living skills in a real workplace setting. During the program, which spans a school year, Project SEARCH participants receive support from both a special education instructor and a job coach. The instructor and coach work collaboratively with the interns on their job assignments and as a group in a dedicated on-site classroom.

Brita and 11 other young adults in the program work a total of four hours each day at one of their three rotations. Participants spend an additional two hours each day in the classroom. Brita is currently working in the hospital's rehabilitation center, where she cleans up after exercise classes and sanitizes the gym equipment and pool area. Her next rotation may have her labelling supplies, stocking hospital rooms, or assembling medical kits. These are just a few of the tasks Project SEARCH interns accomplish throughout the year. Class time reinforces the skills they acquire throughout the internship and adds practical skills like setting goals, being punctual, job interviewing, and even reading a pay stub.

### **Teachable Moments**

According to Chris Dailey, Brita's job coach, Project SEARCH is unique because it provides a series of teachable moments. "Not only are we able to teach a variety of basic living and job-related skills in the classroom," he explained, "we have the distinct advantage of being able to apply many of these lessons on a daily basis. I

feel a lesson may plant a seed, but the teachable moments are truly what allow those seeds to take root."

Examples of teachable moments include: following a schedule; entering a crowded elevator; using the right voice volume; managing time; sanitary practices like washing hands; safety practices; and social skills like making eye contact, speaking clearly, or allowing others time to speak.

According to Shawn O'Connor, the Project SEARCH instructor, two of the biggest achievements he sees from the interns are learning to deal with change and learning to communicate effectively. The interns rotate through different departments and work at three different assignments for 10 weeks each. With each move, they must adapt to new skills and routines and communicate with new people.

### **Lots of Little Things**

Mr. O'Connor and Mr. Dailey continuously make rounds to check on the interns, so they see each intern at his or her work site several times a day. What kind of support do Project SEARCH participants need? According to Dailey and O'Connor, they need lots and lots of little

things. O'Connor and Dailey each learn the interns' unique challenges and seek innovative ways to help each intern succeed on the job. Back in the classroom, interns discuss their jobs and any problems they may have and help each other figure out solutions.

One of the "little things" O'Connor and Dailey do to help the interns is design a color-coding system. Color coding is one way to simplify identification of clean or dirty items and which instruments need to be put together in kits. The "little things" are not insignificant, either. Some of these little things end up helping everyone in the department. Better organization techniques helped one intern stock more efficiently, and in turn, helped everyone throughout that unit save a lot of time.

### **Steps to Employment**

At the conclusion of the Project SEARCH internship program, Vocational Rehabilitation helps participants find employment in the community.

I've always wondered, and often worried, about what kind of employment opportunities will be available to Brita when she finishes school. At the same time, I've always known she would need both real-life experiences and extra time and support to learn job skills. And, that is what Project SEARCH is all about. Brita is not the only one who is happy when she gets on that bus in the morning!



*A Project SEARCH participant makes up a hospital bed during one of her rotations in the year-long program*

Visit [www.projectsearch.us](http://www.projectsearch.us) to learn more about Project SEARCH nationally. For more information about Project SEARCH in Alabama, call (334) 353-7713 or (334) 293-7257.

# Military families and the special education system

by Vonda Reeves, parent consultant

Understanding the special education system is mind-boggling, but for military families, there are two differing systems to choose from.

Traditional neighborhood schools are governed by the Local Education Agency (LEA). A second system is used for military families with children attending school on base and is governed by the Department of Defense Education Activity (DoDEA). Both the DoDEA and the LEA require an Individualized Education Program (IEP) for accommodations, but the DoDEA also uses a Case Study Committee (CSC) to guide the special education process.

Military families should keep these things in mind when selecting a school for their child with special needs:

1. Children with disabilities are entitled to special education or accommodations as needed to help them achieve educational goals.
2. Children under 3 are also entitled to assistance. In Alabama, a child with developmental delays of 25 percent or greater will receive services.
3. Parents have the right to school records.
4. Military families changing schools should receive similar or comparable services at the child's new school.
5. Parents should know how discipline is applied to children with disabilities.
6. Moving may affect SSI (Supplemental Security Income) payments, military pay, and financial aid.
7. DoDEA schools adhere to a different set of standards. Public schools are required to comply with IDEA, while DoDEA schools comply with DoDI 1342.12.
8. Parents can disagree with and challenge any decision made by the school about their child.
9. Parents have some powerful tools they can access in the event of a disagreement.
10. Supplemental funding up to \$36,000 is available to military families for additional therapy and services for children with disabilities.
11. Not all military benefits will work for all cases.
12. Parents of a child with a disability should perform additional legal preparations before deployment.

As always, if you are a military family and have more questions about the educational services your child is receiving, contact your local CRS parent consultant.

## DoDEA (Department of Defense Education Activity) ELIGIBILITY CATEGORIES

### Physical Impairments

Autism spectrum disorder  
Blindness  
Deafness  
Deaf-blindness  
Hearing impairment  
Other health impairment  
Orthopedic impairment  
Traumatic brain injury  
Visual impairment

### Communication Impairments

Articulation  
Fluency  
Language/phonology voice

### Emotional Impairments

### Language Impairments

Intellectual disability  
Specific Learning disability

### Developmental Delay

## IDEA (Individuals with Disabilities Education Act) ELIGIBILITY CATEGORIES

Autism  
Deaf-blindness  
Developmental delay  
(young children ages 3-9)  
Emotional disability  
(formerly emotional disturbance)  
Hearing impairment  
(including deafness)  
Intellectual disability  
(known as mental retardation)  
Multiple disabilities  
Orthopedic impairment  
Other Health impairment  
Specific learning disability  
Speech/language impairment  
Traumatic brain injury  
Visual impairment  
(including blindness)

### According to the DoDEA and public schools, challenges for military families with children in special education are:

- When a child with an IEP moves to a new school district, his/her IEP may not immediately be recognized and enforced at the new school.
- IDEA 2004 mandates that a child must be given a Free Appropriate Public Education (FAPE) and receive "similar services" until an evaluation and IEP are written. Each district interprets this law differently.
- A school district may provide fewer services and ignore the current IEP.
- Sometimes, the evaluation of the child for a disability and special education services is delayed because the family is being transferred or in the process of transferral. When this happens, the deadlines for finishing the evaluation start over at the new location.

### For more information, please visit:

Department of Defense Education Activity  
Specialized Training of Military Parents (STOMP)  
Alabama Disability Advocacy Program (ADAP)  
Alabama Parent Education Center (APEC)

[www.dodea.edu](http://www.dodea.edu)  
[www.stompproject.org](http://www.stompproject.org)  
[www.adap.net](http://www.adap.net)  
[www.alabamaparentcenter.com](http://www.alabamaparentcenter.com)

# Friends of NCBDDD Family Liaison Opportunity awarded to Family Voices

The Friends of the CDC's National Center on Birth Defects and Developmental Disabilities is excited to announce that Family Voices has been selected as its Family Liaison.

The overarching purpose of a Family Liaison is to enhance the reach of the Friends of NCBDDD to families.

Family Voices will advise the Friends and contribute to educational strategies that enhance communication between families and key target audiences of the Friends of NCBDDD, including policymakers, non-government organizations, and service providers. Family Voices brings a national and state presence of family-led health promotion and service programs as well as demonstrated experience in listening to and including the input of families in programs.

Family Voices will encourage involvement of family members, parents, and people living with a disability in Friends of NCBDDD



## Friends of NCBDDD

In Support of the National Center on Birth Defects and Developmental Disabilities

activities in our four thematic focus areas. Many thanks to the review panel, which included several members of the Executive Committee: Angela Blackwell, Roberta Carlin, Mary Andrus, and Patrick Johnson. The Friends of NCBDDD Executive Committee is excited to report that they have collaborated with NCBDDD to develop four Friends focus areas:

- Saving babies through birth defects prevention and research
- Helping children live to the fullest by understanding developmental disabilities, like autism
- Protecting people and preventing complications of blood disorders
- Improving the health of people with disabilities

The Executive Committee needs your help to serve as a Champion in one or more of the focus areas listed above.

As a Champion, you would recruit Friends who have an interest in the particular focus areas as well as have the opportunity to provide content area expertise, join the newly formed Friends Communications Committee to coordinate messaging, and help tailor specific messages for key target audiences.

The Executive Committee is looking for Friends that have expertise in communications, marketing, governmental relations, and family member experience. Friends serve a one-year term, with an option to renew for an additional year. There is also a monthly commitment of one to two hours, including joining Communications Committee calls.

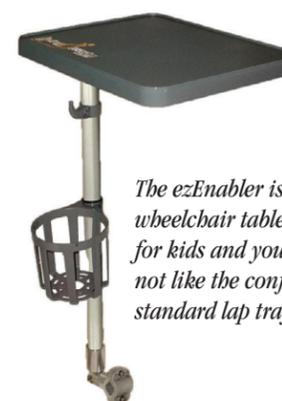
# More cool stuff!

## Handy, inexpensive gadgets to help parents of children with special needs

by Sharon Henderson, parent consultant

Feedback from last issue's "Cool Stuff" article was so positive that we decided to find a few more items that make your life a bit easier for you and your loved ones:

Speaking of easier, the **ezEnabler** by **LivingEazy** is a portable wheelchair table that incorporates a cup holder and a hook for



The ezEnabler is a portable wheelchair table that is great for kids and youth who do not like the confinement of a standard lap tray

carrying everything from keys to grocery bags. I've also found that portable wheelchair tables such as this are great for kids and youth who do not like the confinement of other traditional, and larger, lap trays. The device is easy to assemble and attach to most chairs and is great for eating, reading, and writing, among other things. (\$99 retail or \$75 from Amazon)

For persons who need to keep their head elevated, I've found the **Mattress Genie Bed Lift System** by **Contour** to be a godsend. This innovative wedge inflates to raise and lower your upper mattress with the push of a button. It's a bit noisy, sounding a bit like a vacuum cleaner, but that seems to just add to the fun for the kids. Other bed wedges are available, but none I've found are as adjustable or easy to use as this one. This is a great way to add adjustable bed functionality without purchasing a full hospital



The Mattress Genie adds adjustable bed functionality to any standard flat bed

bed. (approximately \$120 for twin, \$175 for queen from Amazon)

Parents, do you have any additional tips or useful items to share? If so, let us know about it by posting them to our Facebook page, [www.facebook.com/crs.parentconnection](http://www.facebook.com/crs.parentconnection).

## HOLIDAY

*Continued from Page 1*

knew he wasn't going to handle it in that moment.

If you just can't see fitting in at that neighborhood party, don't go. If your child isn't going to be successful in a certain environment, change it to make it work for you. Know when you have too much on your plate and let something go. Going beyond your limits will just increase your stress levels and decrease your enjoyment.

Too often, moms in particular burn the candle at both ends, causing it to burn out quickly. Add to that holiday celebrations, shopping, wrapping, decorating, and dealing with family, and you have a recipe for disaster.

### Continue Normal Routines

Your child's medical needs aren't going to take a break because of a holiday. Last Christmas, my son's stomach pain issues were at their worst. One of our holiday celebrations had him running a Go-Lytely cleanout through his feeding tube for 28 hours. He was miserable, and we ended up inpatient a few short days later. His body didn't get the memo that it was supposed to take a day off from its usual routine.

Take your child's medications and supplies with you. Stick with your child's routines, and don't skip medications or treatments. Put your children to bed at their normal times.

You will still need to take care of you, and that includes not stretching yourself too thin. Try not to schedule in activities or preparing gifts that will keep you up later at night than you usually are. The machines will still alarm in the middle of the night, your child will still wake up at night, and then you will be too exhausted to enjoy your best laid plans. I have found that I just can't be Supermom anymore and need to just settle for Mom. I haven't had a great night of sleep in a very long time, and my son is showing no signs of letting us sleep any time soon.

### Stick to Your Budget When Buying Gifts

Many of the kids that I know today have huge holiday celebrations with more presents than they know what to do with. Not only does it put a dent into the budget, or add to debt, but it also teaches children to expect a grandiose experience each and every time. The focus becomes the gifts they receive instead of time spent together.

One of my favorite holiday traditions came from a friend named Sue. When I first got to know her, her boys were young teenagers, so I'm not sure when they started their tradition. However, her kids don't expect gifts. Instead, they give them. They adopt a family and shower them with loving attention in the form of gifts, food, or other needs they can provide. In place of gifts, they go away together and read letters that they write to each other. Their focus is on time, sharing kind words with each other, and helping others. I've known Sue for over 10 years and they are still continuing this tradition.

Another mom that I talk with online shared that she is doing a "want, need, wear, read" gift idea this year. Her kids will each get four gifts total from their parents. They will get something they want off their lists, something they really need, something to wear, and something to read. That is it.

My son's main gifts all have totaled \$73, including the one that his sister helps pay for. I'm not done with my daughter's gifts, but her end number is heading in the same direction. I have walked away from some things that I wanted to buy for her – like a digital camera – because they were outside my budget. Stockings have one higher cost item in the toe and the rest are dollar type items such as lip balms, stickers, hair bows, or matchbox cars.

My kids have never cursed Santa for his cheap gifts, and neither have I. I am continuing this tradition from my childhood. I will enjoy Christmas more knowing that while it was hard to come up with the extra money for my children's presents, I will not go into debt over a holiday.

If your family cannot afford to buy adult presents then don't do it. Talk ahead of time to your extended family and tell them that you won't be buying adult presents this year. A few years ago, my siblings and I decided that we weren't going to do adult presents any more.

Kids can make crafty gifts for adults so they aren't just receiving presents. These crafts can be as inexpensive and simple as a homemade card or as elaborate as home-crafted soaps. Your children will get the message that giving is important, and the adults will appreciate the heart that went into the gift-making. Oriental Trading Company has great crafts kits for low prices. This year, my kids are making travel coffee mugs for their grandpas. They are inexpensive, but the cups are high quality



and will look great when done.

Keep in mind that what you do today, your kids might try to live up to as parents themselves. I don't want my children thinking that the reason for holidays is the gifts you receive, no matter what the cost. You will enjoy the holidays much more if you don't have debt to look forward to after the festivities are over.

### Family Time is Precious

Focus your energy, time, money, and passion on finding ways to spend quality time together in a manner that will work for your whole family. For us, that tends to be crafts at home. My son doesn't do much of it, but he enjoys dabbling, and it's quiet at home. When I take him out in public, I spend most of my time fighting with his sensory issues, and it can be too overwhelming for him. At home, however, we are all comfortable.

Find a quiet place and get comfortable. I like my bathtub, because I can do aromatherapy at the same time with my favorite bath products. Close your eyes and take several deep breaths until your breathing and heart rate slow to a relaxed state. Try to visualize yourself wearing a heavy backpack on a dark forest trail. While you are slowly walking on this path, reach into your backpack and pull out a rock with a word on it. The words on the rocks will be the stresses in your life. Throw them in the woods, and keep walking.

As you continue to walk, you begin to feel like your load is lightening and the path is getting more lit. At the end of my walk, my backpack is empty, and I am walking into a brightly lit open field. Seated on a throne is God, dressed in a glowing, white robe. Sometimes, I sit at his feet and just feel peace. Other times, I talk to him.

The interesting thing about this process is that I am often surprised by what I see written on the rocks. I don't always realize what is creating stress until I see it written on that rock. It helps for me to identify what I need to eliminate or work on.

Whatever it is, take time for you and find a way to reduce or eliminate stress that can make it hard to enjoy the holidays.

### Don't Stray Too Far

If it will stress you out to gain weight, then don't. Treat yourself on occasion, but limit how often and how much. If you know you are going to a party at the end of the week, be good and stay on your diet all week. Eat a healthy snack before going to the party, so you can sample small bits of the food offered instead of gorging on everything.

Gaining weight that will be hard to lose right after can impact your health and stress levels. If you normally exercise, try to continue it on as many days as you can fit in. Follow your normal routines for keeping you healthy, too.

### Seek Help

If you are struggling financially with the holidays, look for help. Many churches, schools, fire departments, police departments, and local programs adopt families for the holidays. Swallow your pride and ask for help. Our local food banks are planning to provide holiday meal supplies.

Holidays can be emotionally difficult or even depressing for some people. Some churches provide free counseling if you ask. Many

insurance companies cover mental health visits with a therapist. Let friends and family know you are having a hard time. Let someone help.

### Be Prepared for the Unexpected

My husband and I often joke that if it can go wrong, it will. If it's not supposed to go wrong, it will. When it does go wrong, try to laugh instead of getting upset. We're not pessimistic about life, or looking for the next problem in life, but instead we are preparing for the "what if" situations and are relieved when we don't have to face them.

This has been a joke in our house, but so far it has held true. We've been to the ER many times with our son. When we thought for sure that we were going to be admitted, we would pack a bag. Those are the times we were sent home. When we went just to make the doctor happy or expecting to come home, we didn't pack a bag. Those are the times we've been admitted. Now, we joke that by preparing ahead of time for the unexpected that we are heading off disaster.

One thing we do to plan for the unexpected is to take our son's emergency supplies with us to our events. I pack all of my son's "as needed" medications and extra supplies, even when we are just going to my parents' house for one overnight stay on Christmas. We live 30 minutes away, but the event will be so much more fun if we don't have to spend an hour or more driving back to get something he needs. Plus, it helps me not worry about the "what ifs."

### It's About Your Family

The holidays aren't supposed to be about losing yourself and your beliefs in order to make others happy. It shouldn't be something that breaks your family. Take the time this year to decide what it is you want to get from the holidays and stick to it.

It's okay to say no to family. One year, we told all family that we were just going to stay home with no company over for Thanksgiving. Not everyone understood why it was important to us, but we did it anyway and everyone got over it.

You get to choose what messages you want your children to learn about the holidays. Set your limits, make new traditions that work for all your kids, and most importantly, do what helps your family feel connected during the holidays. Take the time to appreciate each other and do for others in whatever ways you can.

## Coverage for children aging out

Families and professionals working with children with disabilities need to know about various insurance coverage options as children age out of programs. Choices may be different depending upon whether the insurance is employer-based, obtained through the Marketplace, or public insurance. (NOTE: Children with special health care needs may be eligible for more than one type of plan.)

### What is Dependent Coverage?

There are several ways families can keep their child under their plan. These are:

Under the ACA (Affordable Care Act), families can continue health insurance coverage for their children until age 26, even if their children are living on their own.

Some states have their own laws, which if more generous, would override federal requirements. For example, dependent coverage is available until age 31 in New Jersey if the dependent young adult is living at home, unmarried, etc.

Using the “disabled dependent provision,” sometimes still called the “certification of the handicapped provision,” a child could be covered regardless of age as long as the parent is employed. Parents can ask their employer’s human resources department for the form, which is important to complete prior to age 18, since coverage, once suspended, cannot be restored.

### Marketplace Plans

As mentioned previously, families can continue dependent coverage until age 26 under the ACA. The Marketplace will only pick one type of plan (Qualified Health Plan [QHP] or Medicaid.) Families can apply for coverage during open enrollment periods, special enrollment situations (e.g. losing a job), or Medicaid any time.

Adult children up to age 26 can stay on a



parent’s plan even if they are:

- married
- not living with their parents
- attending school
- not financially dependent on their parents
- eligible to enroll in their employer’s plan

### Public Insurance

Medicaid provides coverage for individuals who have disabilities or low income. After age 18, the individual is seen as a “family of one” and parental income is no longer “deemed” as part of their income. States that expanded Medicaid under ACA have coverage starting at age 19. This may make it possible to transition from Medicaid for children or the Children’s Health Insurance Program (CHIP) to adult Medicaid, although this is not automatic, so it is necessary to apply. Some children may be eligible for a Medicaid waiver due to their medical status, regardless of family income. Parents can contact their Maternal and Child Health Title V agency or their Family Voices/ Family-to-Family Health Information Center. In most states, if a child is eligible for Supplemental Security Income (SSI), which provides financial aid, they are also eligible for Medicaid.

Medicare offers coverage for individuals older than age 65 or with certain disabilities. Medicare will cover children who have kidney disease and need dialysis or a transplant. Disabled Adult Child (DAC) provisions allow eligibility for Medicare if the child was disabled before age 22 and a parent is disabled, retired, or deceased.

### Other Options for Health Coverage

**Catastrophic Plans:** People younger than 30 are eligible for catastrophic health plans. The plans are called “catastrophic” as they protect against high costs of care for a major illness. The benefits are limited for both primary and preventive care. Catastrophic plans have fewer benefits than QHPs so may not be the best choice for people with disabilities.

**College Plans:** Students are not exempt from the requirement to have insurance that meets certain standards or else pay a penalty, but many college health plans qualify as coverage for this purchase. However, some of these plans may not have as many benefits as QHPs or may not qualify as creditable coverage under the health law. Students should check to see if they are eligible for tax credits to purchase a Marketplace plan. Note that in states that have expanded their Medicaid program, students age 19 and older may qualify for Medicaid.

**Having More than One Plan:** A child may be eligible for a private employer plan as well as Medicaid and/or Medicare as mentioned previously. It is important that there is “coordination of benefits” for all plans to reduce costs for families. If a provider doesn’t participate in Medicare, the doctor can send their “opt-out” Medicare letter to the private insurance company with the bill. Families can even file claims this way. Also, if a provider doesn’t participate in Medicaid but the child also has private coverage, the doctor can contact the insurance plan to find out how to bill “out of network” as secondary.

Families have options available to them as their children “age out.” By checking resources and contacting the organizations listed there, they can determine the best option for their child with disabilities.

To learn more about the Marketplace, visit [www.healthcare.gov/young-adults/children-under-26/](http://www.healthcare.gov/young-adults/children-under-26/). For more on Medicaid expansion, go to: [www.healthcare.gov/medicaid-chip/medicaid-expansion-and-you/](http://www.healthcare.gov/medicaid-chip/medicaid-expansion-and-you/).

## Book Review

### Special Education in Alabama: A Right Not a Favor

provided by The Alabama Disabilities Advocacy Program

by Ree Clark and Sandra Hazzard  
CRS parent consultants

You have a child with special health care needs, and you are seeking answers to questions you have about providing your child with an education. You find yourself lost in the maze of the education system. Where would you even begin?

This book – and others like it – is available for loan in the parent resource centers at CRS offices around the state.

For many parents of children with special health care needs, the Alabama Disabilities Advocacy Program’s (ADAP) publication, **Special Education: A Right Not a Favor** is a great start and an invaluable part of their advocacy for their child. This recently updated book is provided free of charge by ADAP and gives a condensed, yet detailed, guide to special education law and rights provided under the Individuals with Disabilities Education Act (IDEA).

Through IDEA, all children with disabilities in Alabama have a legal right to free and appropriate programs of special education



and related services. This right to children is granted under federal law to protect them from discrimination and isolation as unique learners. IDEA enables children with special health care needs and learning disabilities to receive services and accommodations to better equip them to learn like typical students do. Trying to wade through the law alone would be a daunting, if not impossible, task. This book arms you as parents with information about common concerns or questions you may have, including a better understanding of rights to services for your child, how to advocate for those rights, and

how best to partner with school personnel to help your child achieve his or her maximum potential.

Topics covered in this book include evaluation and eligibility criteria, writing the Individualized Education Program (IEP), transition, behavior and discipline, conflict resolutions, Section 504, and Early Intervention services for infants and toddlers.

**A Right Not a Favor** also includes a helpful selection of sample letters to assist parents in more effective communication of their specific needs or complaints to administrators. The book maps out strategies in shaping their child’s education and encourages parents to become active participants for the journey. The more knowledge parents have going into educational meetings, the better prepared they are to adequately represent and stand up for their child. A solid foundation to forge that path of advocacy and understanding begins with this book.

Of course, CRS knows all of this can be overwhelming to families who already face significant demands and stressors, and we are available to help. Check with your local parent consultant for additional information on this topic or many others.

Copies of this book are available at each CRS office or online at [www.adap.net/RNFComplete%20Book.pdf](http://www.adap.net/RNFComplete%20Book.pdf).

## DIRECTOR

Continued from Page 2

### Q. Which region will my child receive services in?

A. Your child will be assigned to a region by Medicaid, according to where you live in the state (your geographic location). You can see the RCO regions by going to the Medicaid website as instructed below.

### Q. What will happen if I move to a different region after being assigned?

A. If you move to a different region, you must

notify your assigned RCO. Your RCO will tell you the steps to take to continue to receive services.

### Q. Will any of my services change, such as services that are currently provided by CRS?

A. Medicaid wants recipients to continue to receive the same or similar services. CRS meets with Medicaid regularly to talk about the services we provide in an effort to assure that the quality of services received by children with special health care needs remains the same throughout the state.

### Q. How can I learn more about RCOs?

A. Visit the Alabama Medicaid website at [www.medicaid.alabama.gov](http://www.medicaid.alabama.gov), click on *Newsroom*, then scroll down and click on *Regional Care Organizations*. You will be able to read about many of the steps that have already been taken and can even sign up to join the Medicaid email list for updates and/or to email questions to Medicaid. Also, plan to attend any meetings announced in your community to learn more about RCOs.

For information about Family Voices, please contact the Alabama state coordinators, Susan Colburn, 334-293-7041, [susan.colburn@rehab.alabama.gov](mailto:susan.colburn@rehab.alabama.gov) or Jerry Oveson, 251-438-1609, [oveson@bellsouth.net](mailto:oveson@bellsouth.net).

For more information about Children’s Rehabilitation Service and to stay in touch with Parent Connection, please visit us on the web at [rehab.alabama.gov/CRS](http://rehab.alabama.gov/CRS) and [www.facebook.com/CRS.ParentConnection](http://www.facebook.com/CRS.ParentConnection)

# Let's YAC about it!

## The makings of a leader

by Miracle Woods, CRS state youth consultant

Recently I held a teleconference with the Youth Advisory Committee (YAC), and we covered a topic that is very necessary in disability culture: leadership.

The community of people with disabilities is the most-diverse group there is. Disability culture is nurtured when people with a range of disabilities gather and share information and camaraderie over the things they have in common. Leadership is the power or ability to lead others. Good leaders are vital to creating major and profound changes, and leadership is important, particularly for youth with disabilities because of the many obstacles we face.

Just a few days ago, I read through several posts to our CRS Youth Connection Facebook timeline dealing with leadership. In searching, one organization I came across was Young Invincibles. The post I saw detailed the high unemployment rate for youth in Chicago. From there, I happened across another post from



Miracle Woods with Teresa Nguyen, a public health leader and 2014 recipient of the AMCHP Ryan Colburn scholarship

National ADAPT highlighting peaceful protests occurring in Little Rock, Ark., for individuals with disabilities.

So, why take time to mention all of this to you now, you ask? I want to illustrate a clear picture that leadership matters; it's never too early to start. I'm taking time out now to open the YAC discussion on leadership, which I urge you to continue. We range in age from 18-25, and we

all can change something related to persons with disabilities for the better. During the teleconference I participated in, we touched on why serving on a board, like YAC, is important in developing strong leaders and leadership skills. The journey begins with learning and culminates with leadership opportunities.

Leaders spearhead change, big or small. Somewhere inside you lies the potential to lead. You just need to find it.

Keep persevering and aim high!

### To learn more about:

#### Disability culture

[www.kasa.org/resources/files/history-culture.php](http://www.kasa.org/resources/files/history-culture.php)

#### Young Invincibles

[www.younginvincibles.org](http://www.younginvincibles.org)

#### ADAPT

[www.adapt.org](http://www.adapt.org)

#### Youth Leadership

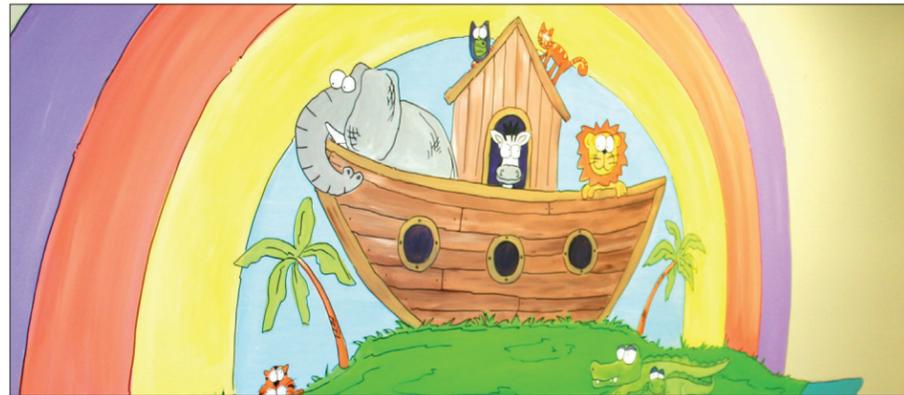
[www.ncwd-youth.info/youth-development](http://www.ncwd-youth.info/youth-development)

[www.ncl-d-youth.info/index.php?id=19](http://www.ncl-d-youth.info/index.php?id=19)

## THE RAINBOW CONNECTION

The halls of the Anniston CRS clinic have been made a bit brighter with the recent addition of several hand-painted murals placed throughout the clinic space.

"The murals have been a big hit," said Randy Whitt, CRS district supervisor. "Our children have absolutely loved them. Parents often take pictures of their children with the animals, and of course our two most popular animals are the Auburn tiger and the Alabama elephant."



Please add me to your newsletter mailing list.

Name: \_\_\_\_\_

Agency: \_\_\_\_\_

Address: \_\_\_\_\_

City/State/Zip: \_\_\_\_\_

Clip and mail to  
Susan Colburn  
Children's Rehabilitation Service  
602 S. Lawrence St.  
Montgomery, AL 36104



# HAPPY HOLIDAYS WORD SEARCH



Created by Sue Lindlauf

P	O	J	A	H	S	E	N	A	C	Y	D	N	A	C
R	S	S	H	O	P	P	I	N	G	M	F	K	A	S
E	E	H	W	L	J	B	L	X	M	A	F	L	H	O
S	I	I	E	I	K	C	F	N	M	D	F	F	G	S
E	V	R	R	D	L	P	O	I	M	A	P	O	S	N
N	O	T	T	A	M	O	L	I	W	L	O	N	X	O
T	M	U	Y	Y	N	Y	U	K	E	O	O	U	A	I
S	O	L	U	S	B	L	W	H	T	I	L	N	T	T
C	H	R	I	S	T	M	A	S	T	I	O	S	N	A
M	P	J	O	W	V	K	A	A	T	U	J	A	A	R
J	A	N	P	Q	L	Q	C	O	O	K	I	E	S	O
B	G	G	Z	I	C	A	O	L	A	T	A	O	P	C
S	X	N	M	S	V	Z	F	R	I	E	N	D	S	E
L	U	D	J	D	Z	M	P	H	O	W	M	P	M	D
F	M	S	K	Y	P	P	A	H	I	E	N	D	S	W

See how many of these words you can find in the puzzle. The words can be forward, backward or diagonal.

- |              |                |                 |            |
|--------------|----------------|-----------------|------------|
| 1. Happy     | 5. Family      | 9. Shopping     | 13. Santa  |
| 2. Holidays  | 6. Friends     | 10. Candy canes | 14. Songs  |
| 3. Christmas | 7. Presents    | 11. Cookies     | 15. Movies |
| 4. Vacation  | 8. Decorations | 12. Milk        | 16. Fun    |



**CRS PARENT CONNECTION**

Children's Rehabilitation Service  
Alabama Department of Rehabilitation Services  
602 S. Lawrence St.  
Montgomery, AL 36104

**PRESORTED  
STANDARD  
U.S. POSTAGE PAID  
Montgomery, AL  
Permit No. 109**



## Check Out What's Ahead ...

### **Nov. 21, 2014**

Christa Hackney, an advocate with Alabama Disabilities Advocacy Program (ADAP), will be at Mobile CRS to answer questions about Disability Rights. For more information, contact Lisa Gibert, parent consultant, [lisa.gibert@rehab.alabama.gov](mailto:lisa.gibert@rehab.alabama.gov) or (251) 439-7869

### **Dec. 11, 2014**

#### **Silent Dinner**

**Description:** The Silent Dinner is a signing-only experience, where you do not use your voice to communicate during the event. A wonderful way to get to know members of the Deaf community, local interpreters, and other persons interested in sign language in the Birmingham area. Dinner begins at 6:30 p.m. at Red Lobster, 1030 Montgomery Highway, Vestavia Hills.

**Information:** Wendy Lozynsky, [lozynsky.wendy@aidb.state.al.us](mailto:lozynsky.wendy@aidb.state.al.us)

### **Dec. 18, 2014**

#### **Huntsville CRS Christmas Party**

**Description:** Santa Claus will be making a special appearance at Huntsville CRS for their Christmas party. The party will include pictures with Santa, arts and crafts, and a toy drive to ensure all kids receive a gift from Santa.

**Information:** Melissa Watson, parent consultant, [melissa.watson@rehab.alabama.gov](mailto:melissa.watson@rehab.alabama.gov) or 256-650-1785

### **April 13-14, 2015**

#### **Fifth Annual Partners in Care Summit**

**Description:** Family Voices of Alabama and the Family to Family Health Information Center project will host the fifth annual Partners in Care Summit at the Marriott Prattville Hotel & Conference Center at Capitol Hill.

**Information:** Visit the Family Voices of Alabama website at [www.familyvoicesal.org](http://www.familyvoicesal.org), or contact Trish Switzer, 1-877-771-3862.

*Local PAC meetings: Check your local CRS office for dates and times of meetings in your area.*