

The Post CARD

*A Publication of the Center for Autism and Related Disabilities
at the University of Florida/ Gainesville*

Fall 2004

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Dear Families and Friends of CARD,

Happy Holidays! We hope the holidays are peaceful and relaxing for you and are not too stressful. Sometimes the disruptions that accompany changes in routine, travel, no school, family visits etc. can be especially difficult for persons with autism and related disabilities. A brief article inside this issue gives the perspective of one person with autism.

We at CARD are busily preparing for the start of 2005. The new year will start with a bang for us with the Annual CARD Conference in Orlando on January 14-16 and the Psychiatry Department Autism Conference in Gainesville on January 21. Look on our website or call our office if you need more information on these events. We will also be taking our Survival Skills workshops to Palatka and Chiefland starting in January.

Further on in the spring, we will be sponsoring our Florida Department of Education regional training workshops. Two are scheduled already and we will get you more information on them in the near future. But in case you want to save the dates on your calendar, there will be a one day workshop on Providing Quality Programs for Young Children with Autism and Related Disabilities in Gainesville on February 11, 2005 and a one day workshop on Inclusion for Students with Autism and Related Disabilities in Ocala on March 18, 2005.

The study of autism spectrum disorders is becoming more and more attractive to researchers throughout the world and the University of Florida is keeping pace. There are currently several research studies that are on-going at UF and several more getting ready to start up this spring. We are working with our colleagues in Medicine, Psychology, Education and Nursing to keep families informed of research opportunities and to further our understanding of autism and related disabilities. We will highlight some of these research projects in our next newsletter to you. In the meantime, if you have any questions about research at the University of Florida, don't hesitate to call us.

Sincerely,

Greg Valcante

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Just What Is a Visual Support Make and Take?

by Kathy Robinson

Most of you have probably heard of a Visual Supports Make and Take and many of you have probably wondered about what they are. I would like to take this opportunity to explain them to you and encourage you to come to one sometime if you think visual supports would be helpful for someone in your family or classroom.

Visual supports are any type of picture, schedule, calendar, environmental cue, body language, sign language, or specially designed tool. We ourselves use visual supports everyday often in the form of words written as "to do" lists, day planners, appointment cards, etc. For those with Autism Spectrum Disorder (ASD) visual supports often involve pictures or objects that are easily recognized and universally understood. A weekly calendar with pictures showing which days are school days, which are weekends, days for going to speech or O.T. appointments can help to make life more predictable and understandable for everyone involved. A visual calendar that is set up and viewed daily can be a big help, especially when a change in the usual schedule will be taking place.

People often think that you have to be creative or have computer skills to make a visual support. When you come to a "Make and Take" you will find that this is not true. You can easily make something to take home with you within an hour or two without needing to be either creative or a computer wizard.

The most common visual support that people make is a morning or bedtime schedule. This is a series of pictures that represent the steps taken to prepare for school or going to bed. The pictures are chosen from a computer program, printed and laminated, and then Velcro is applied to the back. A strip of poster board is then laminated and the pictures are placed (with the Velcro) in the correct sequence on the board. A "stop" or "finished" pocket is placed at the end of the schedule where the pictures will be placed as each step of the schedule is completed. This way each step of the sequence has a visual reminder and as each step is completed it is easy to see what comes next and how much (or little) is left to do to finish the task.

Another simple but effective visual support is a "first/then" schedule. This is a laminated piece of construction paper that has the words "first" written above one column and "then" written above the other. A piece of Velcro is applied below each word and then pictures representing the desired sequence are placed accordingly; i.e. first = homework, then = play outside.

Other types of visual supports that can be made at a Make and Take are choice boards, people locators showing who will be where and when, communication boards, calendars and daily planners. Also rules for home or school can be represented visually. These are just a few examples of the most commonly made items. You can learn how to make any of these with a little help from the CARD staff who also attend these workshops.

There is no charge for attending a Make and Take or for using any of the needed materials. Laminating supplies, Velcro, magnets, computers and software are all available for your use. The only thing that you need to bring is an idea of what you need to make and possibly some pictures of people or favorite toys.

Make and Takes have also turned out to be a nice way for parents to share ideas, network and find mutual support.

If you have the opportunity and would like to learn more, please register to attend a Make and Take near you! They are scheduled for the first Tuesday evening of the month at our Gainesville location and on the third Tuesday of the month in other counties on a quarterly basis. If you have questions about the date for a Make and Take in your area or would like to register for a workshop please call Leannis Maxwell at (352)846-3455. The exact dates can be found on our website (www.card.ufl.edu) or on our training calendar.

Hurricane Relief

Escambia County Schools News Release, December 3, 2004

Workman Middle Receives Donation

D.J. Savarese, a sixth grade student at Grinnell Middle School in Grinnell, Iowa, recently spearheaded a campaign to raise money to aid a school that sustained damage from Hurricane Ivan and to replace some of the materials lost in the school's media center.

D.J., a former Florida resident, wrote an announcement using his talker and then played it over the intercom asking his fellow students to bring in 25¢ each. The students brought in enough quarters to raise over \$330, and the student council, led by President Merritt Meyer, then voted to match the sum. Grinnell Mutual Reinsurance Company also donated over \$300. The total sum collected and donated to Workman Middle School was \$1,100. For more information contact Jeff Pomeroy at 494-5665.

Editor's Note: DJ is a former Gainesville resident whose mother, Emily Savarese, worked for CARD.

CARD UF/Gainesville News

by Cathy Zenko

Last year we had the CARD baby boom. As of December 2004, the baby boom is almost officially over. We wanted to share with you what all of our CARD babies are doing now.

We start with Robbin Byrd's son, Nathaniel Lee Justin Byrd. He started this CARD "pregnancy epidemic" coming into the world on June 26, 2003 weighing 7 lbs 5 oz. He is now a very big, busy 19 month old. He's weighing in at a full 32 pounds and he loves to run, dance and play with his friends, Wyatt and Spencer.

Next up is Hannah Elizabeth Marsh, daughter of Karin Marsh. Hannah joined our CARD family just over a year ago, on December 2, 2003 weighing 8 lbs 13 oz. She is now getting into everything as she crawls around her new house just outside of Chicago, IL. Hannah and all her family are adjusting to the cold

weather in Illinois since they moved in October 2004. Karin reports that Hannah loves playing with her "brother" Chester (the dog) and affectionately calls him "Good Boy".

Isaac Nye Flanagan, son of Jennifer Flanagan was the first baby of 2004. He made his debut on January 20, 2004 weighing 7 lbs. 14 oz. The name Isaac means "he laughs" and according to Jenn, he does so even in his sleep. He's now climbing on everything and rapidly learning the meaning of the word "no" and can tell you "no" by shaking his head when he's about to get into something dangerous. His favorite game is being pushed around the house in the laundry hamper by his daddy.

A few months later, Spencer Alexander Zenko was born on Cinco de Mayo (May 5, 2004) weighing 8 lbs 6oz. He is a happy-go-lucky little guy and loves watching his big brother and laughing. He is now 7 months old and belly crawling all over the place. He has a lot to say (ma, da, ba) and his favorite Christmas carol this year is "All I want for Christmas is my two front teeth" (we all hope they come in soon!).

Patrick Thomas Polefko was left out of last year's article, but he was already in his mommy, Carole Polefko's tummy waiting to join his other CARD brothers and sisters. Patrick was born on June 10, 2004 weighing 7lbs. 15 oz. He is now 6 months old and rolling over, trying to sit up and loves watching his big brothers (Alex and Jack) and sister (Julia).

Finally, Julian Luc Gustavo Clopton, son of our computer consultant, Kurt Clopton, was born July 6, 2004 weighing 8 lbs 4.5 oz. Julian is now in his first few weeks of eating solid foods, an ability

he took no time in mastering. He's pictured in official Packers clothing, an item that all babies born in the state of Wisconsin are required to own.

We cannot say the CARD baby boom is officially over until Caroline Raye, our former co-worker gives birth to her second child, due any day now.

Editor's Note: A little surprise for the rest of the staff - the CARD baby boom is alive and well. Jennifer Flanagan just informed me that she is expecting her second child in May!



Nathaniel



Hannah



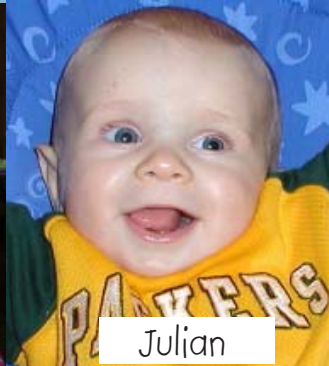
Issac



Spencer



Patrick



Julian

Hoilday Letter from a Person with Autism

This article appeared in the holiday 1999 issue of ASAP News! (Volume 3.5) The Autism Support and Advocacy Project, and Potential Unlimited Publishing. It was written for the purpose of being sent to relatives and hosts of holiday gatherings who might need a crash course in what to expect from their guest with autism.

Dear Family and Friends:

I understand that we will be visiting each other for the holidays this year. Sometimes these visits can be very hard for me, but here is some information that might help our visit to be more successful. As you probably know, I am challenged by a hidden disability called Autism, or what some people refer to as a Pervasive Developmental Disorder (PDD). Autism/PDD is a neurodevelopmental disorder which makes it hard for me to understand the environment around me. I have barriers in my brain that you can't see, but which make it difficult for me to adapt to my surroundings.

Sometimes I may seem rude and abrupt, but it is only because I have to try so hard to understand people and at the same time, make myself understood. People with autism have different abilities: Some may not speak, some write beautiful poetry. Others are whizzes in math (Albert Einstein was thought to be autistic), or may have difficulty making friends. We are all different and need various degrees of support.

Sometimes when I am touched unexpectedly, it might feel painful and make me want to run away. I get easily frustrated, too. Being with lots of other people is like standing next to a moving freight train and trying to decide how and when to jump aboard. I feel frightened and confused a lot of the time. This is why I need to have things the same as much as possible. Once I learn how things happen, I can get by OK. But if something, anything, changes, then I have to relearn the situation all over again! It is very hard.

When you try to talk to me, I often can't understand what you say because there is a lot of distraction around. I have to concentrate very hard to hear and understand one thing at a time. You might think I am ignoring you--I am not. Rather, I am hearing everything and not knowing what is most important to respond to.

Holidays are exceptionally hard because there are so many different people, places, and things going on that are out of my ordinary realm. This may be fun and adventurous for most people, but for me, it's very hard work and can be extremely stressful. I often have to get away from all the commotion to calm down. It would be great if you had a private place set up to where I could retreat.

If I cannot sit at the meal table, do not think I am misbehaved or that my parents have no control over me. Sitting in one place for even five minutes is often impossible for me. I feel so antsy and overwhelmed by all the smells, sounds, and people--I just have to get up and move about. Please don't hold up your meal for me--go on without me, and my parents will handle the situation the best way they know how.

Eating in general is hard for me. If you understand that autism is a sensory processing disorder, it's no wonder eating is a problem! Think of all the senses involved with eating. Sight, smell, taste, touch, AND all the complicated mechanics that are involved. Chewing and swallowing is something that a lot of people with autism have trouble with. I am not being picky--I literally cannot eat certain foods as my sensory system and/or oral motor coordination are impaired.

Don't be disappointed if Mom hasn't dressed me in starch and bows. It's because she knows how much stiff and frilly clothes can drive me buggy! I have to feel comfortable in my clothes or I will just be miserable. When I go to someone else's house, I may appear bossy and controlling. In a sense, I am being controlling, because that is how I try to fit into the world around me (which is so hard to figure out)! Things have to be done in a way I am familiar with or else I might get confused and frustrated. It doesn't mean you have to change the way you are doing things--just please be patient with me, and understanding of how I have to cope. Mom and Dad have no control over how my autism makes me feel inside. People with autism often have little things that they do to help themselves feel more comfortable. The grown ups call it "self regulation," or "stimming." I might rock, hum, flick my fingers, or any number of different things. I am not trying to be disruptive or weird.

Again, I am doing what I have to do for my brain to adapt to your world. Sometimes I cannot stop myself from talking, singing, or doing an activity I enjoy. The grown-ups call this "perseverating" which is kinda like self regulation or stimming. I do this only because I have found something to occupy myself that makes me feel comfortable. Perseverative behaviors are good to a certain degree because they help me calm down.

Please be respectful to my Mom and Dad if they let me "stim" for a while as they know me best and what helps to calm me. Remember that my Mom and Dad have to watch me much more closely than the average child. This is for my own safety, and preservation of your possessions. It hurts my parents' feelings to be criticized for being overprotective, or condemned for not watching me close enough. They are human and have been given an assignment intended for saints. My parents are good people and need your support.

Holidays are filled with sights, sounds, and smells. The average household is turned into a busy, frantic, festive place. Remember that this may be fun for you, but it's very hard work for me to conform. If I fall apart or act out in a way that you consider socially inappropriate, please remember that I don't possess the neurological system that is required to follow some social rules. I am a unique person--an interesting person. I will find my place at this celebration that is comfortable for us all, as long as you'll try to view the world through my eyes!

Sibshop Update

by Jennifer Flanagan

SIBSHOPS ARE BACK!!! On Saturday, January 22 we will have a Sibshop for ages 8 - 12 at SunCountry Sports Center West in Gainesville. There will be rock climbing, gymnastics, food and fun! If you have a sibling 8- 12 years of age who would like to be invited please call me at 352/392-4172. Keep an eye out for upcoming sibshops in the Post CARD.

Contact : Jennifer Flanagan
Email : jnye@mbi.ufl.edu
Phone : 352/392-4172

If you would like to learn more about Sibshops please see our website.

<http://www.card.ufl.edu/cardcalendar.html>

You will find our brochure on Sibshops and an article about the relationships of autistic children and their siblings and the increase of sibling support groups across the nation.

Local Support Group Information

Alachua County

Alachua County parents, please join a new parent support group. This informal group will give you an opportunity to meet other parents in similar situations. You will get to share your struggles and triumphs and learn other ways to cope and move forward. The dates, times and locations are as follows:

1/21/05	7PM-9PM	CARD Office
2/18/05	7PM-9PM	CARD Office
3/18/05	7PM-9PM	CARD Office
4/15/05	7PM-9PM	CARD Office
2/4/05	10AM-12PM	Millhopper Library
3/4/05	10AM-12PM	Millhopper Library
4/1/05	10AM-12PM	Millhopper Library

Please call the CARD office for contact information.

Columbia County

In January, we'd like to help parents form a group for Columbia and possibly surrounding counties that would meet at a central location in Lake City. If you are interested in helping to get this started, please call Jennifer Flanagan at 352/392-4172.

Hernando County

H.A.P.P.E.N - The Hernando Autism Parenting and Personal Experience Network will be meeting on the 3rd Wednesday of every month to discuss a different topic pertaining to Autism Spectrum Disorder. Grandparents, as well as parents of children who have yet to receive a diagnosis are welcome to join the discussions.

Location: Pediatric Therapy Works

Time: 7:00PM - 8:30PM

Please note that there is no childcare, however, the meetings are free of charge.

For more information, and to register, please contact Leslie Bolen at (352) 683-0209

Marion County

Helping Hands - This parent support group is open to parents of all special needs children. You are invited to join your peers to gather valuable information and share thoughts, feelings, experiences and ideas. Please call Sylvia Miller at 352/687-2257 if you have any questions.

Last Tuesday of every month, 6:00PM - 8:30PM

Location: Green Clover Hall

Marion County Governmental Complex

319 SE 26th Terrace

Ocala, FL

**If you have information about other support groups in our area please
let us know so that we can add them to our website.**

Top Ten Tips for Choosing a Toy for a Child with a Disability

From www.lekotek.org

Selecting a toy for a child with disabilities? Here are the questions that the play experts at the National Lekotek Center ask when choosing developmentally appropriate toys for differently-abled kids.

1. **Multi-sensory appeal** - Does the toy respond with lights, sounds, or movement to engage the child? Are there contrasting colors? Does it have a scent? Is there texture?
2. **Method of activation** - Will the toy provide a challenge without frustration? What is the force required to activate? What are the number and complexity of steps required to activate?
3. **Places the toy will be used** - Will the toy be easy to store? Is there space in the home? Can the toy be used in a variety of positions such as side-lying or on a wheelchair tray?
4. **Opportunities for success** - Can play be open-ended with no definite right or wrong way? Is it adaptable to the child's individual style, ability, and pace?
5. **Current popularity** - Is it a toy that will help the child with disabilities feel like "any other kid?" Does it tie in with other activities like books and art sets that promote other forms of play?
6. **Self-expression** - Does the toy allow for creativity, uniqueness, and making choices? Will it give the child experience with a variety of media?
7. **Adjustability** - Does it have adjustable height, sound volume, speed, and level of difficulty?
8. **Child's individual abilities** - Does the toy provide activities that reflect both developmental and chronological ages? Does it reflect the child's interests and age?
9. **Safety and Durability** - Does the toy fit with the child's size and strength? Does it have moisture resistance? Is the toy and its parts sized appropriately? Can it be washed and cleaned?
10. **Potential for interaction** - Will the child be an active participant during use? Will the toy encourage social engagement with others?

Training Information

January 4, 2005	Communication Make & Take (Gainesville)
January 11, 2005	Medications and ASD (Gainesville)
January 11, 2005	Benefits and Employment in 2005 - Medicaid, Medicare, Social Security, and SSI (Gainesville)
January 14-16, 2005	12th Annual CARD Conference (Orlando)
January 18, 2005	Communication Make & Take (Lake City)
January 21, 2005	University of Florida Department of Psychiatry 6th Annual Autism Conference (Gainesville)
January 25, 2005	SURVIVAL SKILLS SERIES -Topic 1 (Palatka)
January 27, 2005	SURVIVAL SKILLS SERIES -Topic 1 (Chiefland)
February 11, 2005	Providing Quality Programs for Young Children with Autism and Related Disabilities (Gainesville)
March 18, 2005	Inclusion for Students with Autism and Related Disabilities (Ocala)

Please see our website - <http://www.card.ufl.edu/cardcalendar.html> - for complete details on the trainings listed above. If you do not have access to the internet please call Leannis Maxwell at 352/846-3455 or 800/754-5891 and she can mail you the information.

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Go to

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for information about:

- *current news about autism and related disabilities
- *support groups
- *trainings and more!