

# A C T Autism Community Together

## Summer Help for Families

Area individuals with autism received help during Summer of 2004. Thanks to a grant from Parkview Hospital and our Walk-to-Talk title sponsor, Lutheran Hospital, twelve individuals with autism received 8 weeks of summer speech therapy. Proceeds from the 2004 Walk-to-Talk also provided 5 summer scholarships to the Learning and Development Center. Other sponsorships included occupational therapy and recreational activities. Summer programming is crucial due to the need for year round intervention.

## 2004 Walk-To-Talk Raises \$48,594



What a wonderful 2 days! First of all let us thank all who made it possible—volunteers, walkers, dedicated friends and family members. The weekend began on Friday night at the beautiful Sycamore Hills Country Club. The Walk to Talk pre-event dinner began the weekend with an inspirational vocal performance

by Tom Didier, city councilman and father of a son with autism followed by great food, a presentation on autism, a silent auction, and an appearance from Sarah Fisher, Kelley Racing Driver of the Cure Autism Now Car. The following morning, over 300 walkers joined forces on the campus of the University of St Francis to walk for a cause so dear to us. The day was filled with festivities, including another performance by Tom Didier, games, crafts, and sensory activities for the children, pizza

from Dominoes, fun with Kelly the Clown and interactive entertainment from juggler and unicyclist, Lance Weirick. Overall, the two-day events raised \$48,594 and we were able to fund all the summer programming requests that we received. We want to thank every participant for making a difference in the lives of these incredible individuals with autism and their families. Mark your calendars now for Saturday, April 20, 2005 for our 2<sup>nd</sup> annual Walk-to-Talkzrttctyuc jtukje jn. If you would like to help in the planning of this exciting event please



## Autism and Grief

I feel relief - Finally a diagnosis. I feel panic – what does the future hold, now that there finally is a diagnosis?

How many of us have gone through the agonizing period of time when we didn't know what was wrong, knowing that something was really not right, but being unable to put a name to it?

I liken the experience to a roller coaster ride – the ups and downs in a situation that we cannot control, careening, seemingly, at breakneck speed. We didn't ask to take this ride, and we know that we cannot escape, even though we are screaming inside for the ride to stop.

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### Up and Coming Events:

- ♦ Saturday September 18th, Answers for Autism Walk, Indianapolis, IN.
- ♦ October 9th at 7PM LDC presents "Roll with the Stars" casino night. For more information call 704-0683.
- ♦ Monday October 18th, Beverly Vicker of IRCA talks on high-functioning verbal students at Perry Hill Elementary School.
- ♦ Wednesday November 10th at 9 AM, LDC presents "Breakfast of Hope" at the Fort Wayne Country Club.

**For more events, consult our website**

## Recently Released Resources

### ***Souls: Beneath and Beyond Autism Calendar for 2005***

The Souls book and DVD have moved us all with its powerful message and inspiring photographs. Just recently released is a calendar, which includes some of our favorite portraits as well as previously unpublished images. This calendar also lists 120 practical strategies for parents and educators. This calendar can be purchased through Starfish Specialty Press ([www.starfish.com](http://www.starfish.com)).

### ***Super Silly Sayings that are Over Your Head-A Children's Illustrated Book of Idioms*** by Catherine S. Snodgrass

How many times do we catch ourselves saying something we really don't mean?? For the child with autism, idioms can be very confusing due to their literal interpretations. This book is illustrated in full color and provides a kid friendly explanation of the literal and actual meanings of some of the most common idioms used today.

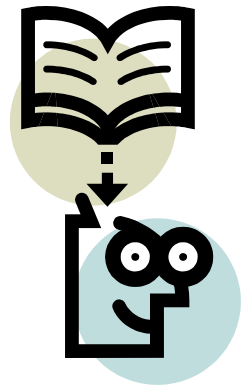
This book is a great tool for all children but especially those with autism as they expand their repertoire of language skills. This book can also be purchased from Starfish Specialty Press.

### ***Autism Spectrum Quarterly***

This publication was formerly the Jenison Autism Journal started by Carol Gray with the Jenison Public Schools. Current Editor-In-Chief, Diane Twachtman-Cullen, PhD, CCC-SLP along with Senior Editor, Liane Holliday Willey, Ed.D. intend to carry on the tradition of publicizing important information and articles for the autism community while also expanding it to include new features such as spotlights on best practices, tips and strategies, book reviews and resources, contributions by well-known professionals in the autism field, and current research updates. Visit [www.ASQuarterly.com](http://www.ASQuarterly.com) for more information.

### ***Ask and Tell: Self-Advocacy and Disclosure for People on the Autism Spectrum***

This book just released this summer is edited by Stephen Shore, author of *Beyond the Wall-Personal Experiences with Autism and Asperger Syndrome* and well-known national speaker. Stephen gave an inspiring presentation for us last April and has proven to many how individuals with autism can reach their fullest potential. This book includes a foreword by Temple Grandin as well as contributions from other adults on the autism spectrum. It discusses the important issues of self-advocacy and disclosure to assist the individual to pursue an independent and fulfilling life. It can be purchased from the Autism Asperger Publishing Company ([www.asperger.net](http://www.asperger.net)).



## Making the Connection

### ***Help Wanted***

*Tutor/Teacher wanted for a 20 month old:* Experience in the areas of psychology, special education, or related disciplines preferred but not necessary. In order to help him learn his parents are establishing a home-based applied behavior analysis program to address his developmental delays. The program is under the direction of a professional consultant and focuses on social, cognitive, and language skills. The program

offers tutors the opportunity to learn the basic principles of applied behavioral analysis and how to teach children with developmental delays with these principles. Contact Marian at (260) 434-0655.



### **ABA Therapist Available**

Erin Lanka has experience with working with a family using ABA for two boys ages 1 and 3. Contact her at (513) 720-4946, 2037 Bayview Drive, Fort Wayne, 46815 or by e-mail at [erwood22@yahoo.com](mailto:erwood22@yahoo.com).

### **Valparaiso Area**

Stacey Van Eck moved to the Valparaiso area in August to begin her graduate studies at the university and has several years of experience doing in-home one-on-one ABA therapy. Contact Stacey at (219) 513-0119 or [Stacey\\_lynn\\_10@hotmail.com](mailto:Stacey_lynn_10@hotmail.com).

## Autism and Grief—continued from page 1

If this description sounds familiar, please allow yourself to accept that the feelings you feel and have felt, are human emotions – not right or wrong, but human emotions, needing to be expressed.

As a grief and loss counselor, I work with clients who have experienced all kinds of losses. Those losses may include the death of someone loved, divorce, the loss of a job, health issues, the aging process itself, and many, many others that we don't even identify as a "loss". Loss is part of the life experience. Even when we acknowledge that fact, it doesn't make the loss less painful. Every loss that we experience needs to be acknowledged, and with that acknowledgement, the work of grief and mourning begins.

When our child is diagnosed with autism, we, as parents experience so many emotions that often we can't sort through them. We may go through various "stages" of grief, as some authors have identified – denial, anger, bargaining, depression, acceptance. We all have expectations

for the future - what life will be like - should be like - and when our life experiences don't meet those expectations, we struggle to understand, to "logic it out". We want answers to the "why" questions. Why us – why our child – why did this happen? Often there are no answers, but it is important that we pose the "why" questions. In doing so, we begin to move from the "why's" to the "how's". How are we going to deal with this, how can we find help for our child, how can we prepare for a future that is relatively unknown to us?

When we hear the diagnosis of autism, we are confused, hurt, anxious, fearful. We may even feel

guilty. Yes, guilty. What did we (I) do to cause this? We may do a lot of reading and research, and our brain understands that "we" did nothing to cause this condition in our child, but that doesn't mean we don't struggle with the "what ifs". I'm talking about the feelings, not the thoughts. It is important that we allow those feelings to come out in healthy ways. Hopefully we have people in our lives to whom we can express those feelings, without their judgment, their advice (even though we haven't asked for it), and their "you shouldn't feel that way" offerings. We may have loving friends and family members who mean well, but they don't understand what we need from them. That may be simply "being there", letting us cry, rage and process what is going on in our struggle to cope with the situation that is now ours to deal with.

That is how grief work is done. We acknowledge the loss, in effect, "honor" the feelings, we express the feelings in a healthy way, and reconcile the loss into our lives. To push the feelings aside is the worst thing we can do.

The following are a few suggestions that might help one cope with an extremely difficult situation:

We can work through our anger, if that is what we are feeling, by journaling (putting our feelings, not thoughts, on paper or in our computer). We can throw things, making sure to consider "Dar's three rules of healthy anger processing". Those rules are:

1. Do no harm to one's self
2. Do no harm to another person
3. Do no harm to another person's property

Exercise is a great way of dealing with frustration and anger. Not only does it help release some of our emotional tension, but our physical

body takes more oxygen, thus meeting our system's requirement to operate at peak performance.

If you have found strength in your faith in the past, turn again to that faith. Spend time with your priest, rabbi, minister or someone of your faith. If you are feeling abandoned by your faith, know that you have found comfort and solace in it the past and it is there for you again. Good nutrition is a must. Stress sometimes undermines our appetite – we either attempt to comfort ourselves with food or we don't follow a healthy diet.

Good sleep habits are often difficult to maintain when we are faced with an unknown future. Carving out some quiet time for meditation and/or prayer before retiring is often helpful in obtaining a restful night's sleep.

A visit to our physician might be in order to make sure that the stress we are experiencing is not causing us physical problems.

We need to be kind and gentle with ourselves and not ask more than we are able to give. Often we just need someone to validate what we are feeling. That validation can come from loving family and friends, or in a more professional setting with a counselor or a therapist.

Know that we can't take care of anyone else unless we take care of ourselves. That does not mean that we are selfish or egotistical. It means that we must fill our emotional reservoir when it is empty or we won't be able to help others. That means our spouse, our child, our friends.

I ask that you be as kind, gentle, compassionate and loving with yourself as you would be with your best friend if they were experiencing this most difficult journey.

Be good to yourselves, friends.

*Written by Dar Richardson, Grief and Loss counselor in private practice in Fort Wayne, IN, (260) 432-0317*



## News of Hope

On July 30<sup>th</sup>, 2004 Medical News Today ran an article that brings a ray of hope for those of us awaiting a cure for Autism. The article reports that a team of brain scientists at Carnegie Mellon University and the University of Pittsburgh have discovered a biological basis for Autism. The discovery revolves around the white

matter in the brain, which is responsible for communication between different areas of the brain. The article stated “Eventually pharmacological or genetic interventions will be developed”. The job ahead of researching the developmental neurobiology and genetics of the brain connection will not be a small one; however,

it is comforting to know that the cause of autism is being researched and that progress is being made. To read the whole article, go to:

<http://www.medicalnewstoday.com/meicalnews.php?newsid=11412>

## Child with Autism MISSING ->

After a nice dinner out, a friend from out-of-town visiting the area phoned to asked if I knew a 10 year old boy named “Russell” with autism? I didn’t. My friend saw Russell in a field at the intersection of Interstate 69 and US 24 after dark on Monday night stimming in a puddle. She of course called 911, but thought I might know his last name off the top of my head. The boy was only able to provide his first name. He did not know his address or his parents’ names or phone number. He had no ID bracelet. He was not keen on cooperating with my friend and kept repeating “Go to Meijer. Go to Meijer.” The police arrived and had had no reports of children missing. Perhaps the parents are out looking for him—so they remained in the area where he was first found. A passer by said, “That may be my neighbor, but I have only ever seen him from afar.” At this moment, the police began to contact the public schools and area agencies in an attempt to identify the boy. Unfortunately there is no registration system like there is for Alzheimer’s patients. The story had a happy ending and the boy was returned to his home safely. Apparently he had been gone for over an hour.

As the parent of a young child with Autism, this incident stirred me and my husband. What would we do? We have buzzers on the door so we know when they are opened. All of our neighbors

know our son and would return him promptly. But would our son give a

“What would you do if you found a missing child with Autism? Or worse yet, lost your own.”

### ***What if you lose your child when traveling?***

Call 911—if you have your cell phone and it is equipped with GPS, the call will be routed to the appropriate law enforcement authorities.

### ***What will the police do to locate my child?***

In Allen County, the procedure is first to come to your home, interview you and search your home.

### ***What action can I take to expedite finding my child if they are at risk for wandering off?***

Contact your local law enforcement agency to inform them of your child’s disability, permanent information regarding specific behaviors or health issues, etc. In Allen County, there is a database which lists known residence—be it children with special needs or an adult with Alzheimer’s

Consider if your child needs an ID bracelet.

stranger his last name, phone number, address, etc.? Lucky for him he was asleep didn’t have to be drilled for the answers that night. What about at school? Sunday school? Then my thoughts turned to the best selling book “A Curious Incident of the Dog in the Night-Time” by Mark Haddon. The book tells a story about a boy with autism who has an unpleasant encounter with the police. The experience was certainly awake up call. When doing my research, I found an interesting website entitled “Police and Autism: Avoiding Unfortunate Situations” which covers the missing child issue as well as a host of other things I never considered. [Http://policeandautism.cjb.net/](http://policeandautism.cjb.net/). The website author, Dennis Debbaudt, has also written a book entitled “Autism, Advocates and Law Enforcement Professionals.” I also called the sheriff’s office to see what their procedures and recommendations were for such scenarios. As it is ACT’s mission to engage and support those who surround individuals with Autism and their families (e.g., law enforcement), I am curious on what you would like us to do vis-a-vie law enforcement. Do you see a need for a voluntary “special needs” registry to be established to expedite the return of lost individuals? Do you want to attend a lecture by law enforcement? Please send your thoughts to us at [www.ACTpositive.org](http://www.ACTpositive.org) or call us at (260)609-7412.

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## Sensory Defensiveness

Deborah Edwards, Occupational Therapist

### ***In Spring 2005, ACT hopes to host a Sensory Integration Seminar***

One joy of parents is to see their child engaged joyfully in any activity. Outward expressions of joy during an activity are different from one child to the next. But, parents know when their child is happy, and when their child “connects” with the purpose of the activity. This is when true learning occurs. Joyful investigation of physical properties of how blocks fall or invention of how a box can be used to access a trapeze is important in learning how objects relate to one another. The noise, texture, or force of the blocks falling on a child’s arm and the feeling of jumping off a box while hanging onto a trapeze is part of the exuberance that a boy or girl can have. Many things prevent a typically developing child from fully engaging joyfully in an activity. Autistic children have another hurdle to overcome. Generally, there can be an interruption of sensory processing in the autistic child. If a child does not receive or interpret sensory information accurately, the child cannot be expected to have a typical response.

Sensory processing is very complex, but simply speaking for the purpose of this article, it has several components. One component is the process of receiving sensory information into the nervous system. Another component is the process of the “receptors” to communicate the information throughout the nervous system that will enable a child to move his or her body, making a response to the stimuli. But, if the sensory information is not received accurately, the nervous system cannot possibly interpret the information.

Receiving information properly, as it was intended, is a critical component for anyone. The autistic child also has difficulty reading “social cues” with some situations that may be loaded with sensory stimuli, such as walking in a dimly lit hallway and lightly brushing against others in line on the way to the library. Unintentional touch may occur, even if it was caused by the child’s own actions such as moving too quickly or slowly in line.

Pat and Julia Wilbarger refer to sensory defensiveness as “*A group of behaviors resulting from a negative response to apparently meaningless or harmless sensory input*”. Pat is a neuroscientist

and occupational therapist who has worked with A. Jean Ayres and Stanley Greenspan throughout her career. Julia is her daughter and an occupational therapist who has partnered in continuing the development of the approaches of the “Wilbarger Protocols”.

There is much clinical evidence to support the protocols that include deep pressure and oral defensiveness procedures; however, the research has not yet been conducted. Neuroscience supports the theory, and the clinical evidence of success with many children supports its continued use. Clinicians, typically occupational therapists, learn the protocols in special workshops that are both lecture and lab. The lab is exhaustive in small groups so that each participant demonstrates competence to use the protocols. Participants also practice the interview process for caregivers.

It is the interview process with all caregivers that identifies the specific “group of behaviors” that determines if Sensory defensiveness is part of a child’s sensory processing difficulties. Once it has been established that Sensory defensiveness is present, a plan can be made to equip the child to accurately “receive” sensory information, so that it is not misinterpreted. Part of the plan might be to use the Wilbarger Protocols, although this is not always the case.

Many parents of autistic children have learned early to offer specific routines and sensory activities at strategic times for their child. The involvement of the clinician at this point may be to help to “tweak” the routines. Pat Wilbarger has coined these routines as “sensory diets”. If the conditions are right to include a deep pressure or oral defensiveness protocol, then the clinician may include it into the sensory diet. Clinicians are trained to provide extensive follow-up with caregivers during the process of establishing a complete program. Several sessions may be needed to complete an evaluation including additional time to discover the specific cluster of behaviors contributing to the sensory defensiveness and the specific routines currently in place. Keep in mind that the desirable long-range outcome is for the child to engage joyfully into play and learning activities regardless of the sensations that may come in contact with his body. Sensory defensiveness is crippling for the student who is also struggling with other disabilities such as a visual impairment or communication disorder. Parents and caregivers are most often the ones who notice these behaviors, which typically are either flight, fright or fight “negative responses to apparently meaningless or harmless sensory input.”

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Engaging and Supporting those  
surrounding those impacted by  
Autism Spectrum Disorder.



ACT's role is to engage and support individuals, families, medical professionals, therapists and educators on effective methods to improve the lives of individuals with autism and their families in Northeast Indiana. By focusing on the front line service providers and high-tech solutions, we will be able to build communities of providers and promulgate best practices for enhancing the lives of people with autism. ACT's key programming consists of:

- Parent Mentor Network
- Lecture Series featuring local personalities
- Workshop Series for families and providers
- Community website

In addition to these initiatives, ACT is working on community development projects with educators and medical professionals.

## Up and Coming Conferences

**Dr. Vincent Carbone's Workshop #4: Teaching Verbal Behavior - Hands-on Training for Tutors & Therapists**, Tuesday and Wednesday October 5th and 6th, Lutheran Hospital.

**Tony Atwood presents "Asperger's Syndrome 2004"**, Thursday October 14th at the Scottish Rite, Fort Wayne, IN.  
**1-2-3 Magic with Thomas Phelan, Ph.D.** ( a registered clinical psychologist and an internationally renowned expert on

child discipline and Attention Deficit Disorder, for more information click [here](#)), Saturday October 16th at the League for the Blind and Disabled presented by the Down Syndrome Association of Northeast Indiana.

IN\*Source Annual Parent & Regional Paren Resource Conference, **Journey to Success: Working Together to Bridge the Gap**, Friday and Saturday October 22 and 23rd at the Fort Wayne Marriott.

**Due Process: You've thought about**

**it, but do you understand it?** Hear from professionals on both sides - attorneys who represent parents as well as schools in Indiana will be present to explain the process and answer questions. Monday November 8th at Kachmann Auditorium in Lutheran Hospital at 7PM. This program is free. To register, e-mail [info@ACTpositive.org](mailto:info@ACTpositive.org) .

## Sensory Defensiveness (continued)

How can a caregiver get help? Number one stop is the physician because the physician needs to know your child and what you are observing. Then if other professionals currently

service your child, show them this article and ask if they can research this for your child. Because not all occupational therapists have had this training, search for one who has. If necessary, meet with your

Director of Special Education to see if the occupational therapist in your school can attend a training on sensory defensiveness.