



ACT Autism Community Together of Northeast Indiana

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Winter 2004

Free Services for Families

It is projected that nearly 100 children will be diagnosed in 2004 with Autism Spectrum Disorders in Northeast Indiana. The intensive nature of teaching these children, the supply of adequately trained professionals and paraprofessionals is not keeping pace. Accordingly, ACT initiated a sponsorship

program for individuals who want to be trained to work with individuals with autism. To ensure that the sponsored individuals implement their newly acquired skills, each must agree to provide free service to a family in Northeast Indiana. Families interested in benefiting from these free services should contact the Autism Com-

munity at info@ACTpositive.org or by calling (260) 609-7412. The ultimate objective of this program is to improve the quality and quantity of providers in our community. By better matching supply and demand, economic theory would say services will become more affordable.

Waiver Services Reduced

Effective March 1, 2004, cost containment measures are forcing changes to waiver services. For example, community-based, educational and therapeutic activities (CETA) will be eliminated for Autism, Support Services and Development Disability (DD) Waivers. CETA funds include such items as attendance at camps, tuition and registration fees for classes, etc. Community Habilitation and Participation Services for Individuals (CHPI) funds available on the Autism and DD waivers are capped at 25 hours per month and service definition will be strictly enforced. CHPI funds include supervision, training, monitoring, education, demonstration or support to assist with the acquisition and retention of skills in the areas of leisure, community events, education, hobbies, volunteer experience, maintaining contact with family and friends and maintenance and management of housing. Taking leisure activities as an example, they will only qualify if it is therapeutic in nature and not simply diversional. More changes are anticipate. Accordingly, it is essential that waiver beneficiaries review their

Take Your Knowledge of Autism to the Next Level

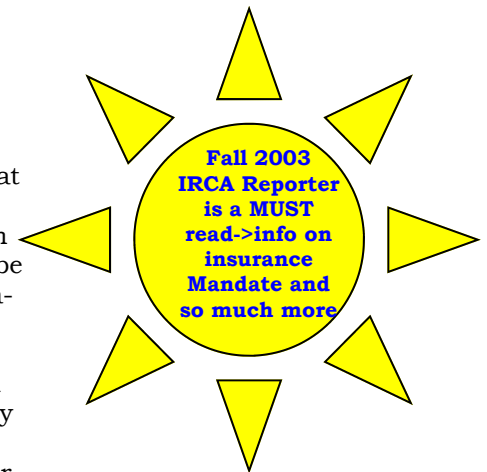
On Friday March 5th, ACT will sponsor a one day seminar entitled "Practical Tools for Teaching Children with Autism" presented by Kim Davis and Melissa Dubie from the Indiana Resource Center for Autism. The day will focus on practical information for instructing individuals with autism within a general education environment. Attention will be

paid to exposing attendees to the wide range of individuals with autism and the diversity of their needs. Topics such as movement differences, messages of behavior, and instructional strategies will be addressed. The seminar will conclude with a panel of local adults with autism telling their stories and answering your questions. This seminar is de-

signed for those who may have a general education focus and limited exposure to children with autism—the general education teachers, administrators, counselors, paraprofessionals, preschool teachers, students or parents. Advanced registration is required. For application may be download from www.ACTpositive.org or by calling (260) 609-7412.

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Up and Coming Events:

- Friday, March 5th, Take Your Knowledge of Autism to the Next Level
- Friday March 12th, LDC's host its annual "Reaching for the Stars" Auction at the Fort Wayne Country Club starting at 6:30 PM
- Monday, March 15th, Scott Bellini on Socialization and Social Skill instruction.

Check the ACT website for the new community calendar featuring these and more local events.

*** Autism Awareness ***

April 2004 will be marked this year with much activity:

Wednesday April 7th is Autism Night in the Haegermann Construction Zone at the Fort Wayne Komet's.

Monday April 12th, Autism Appreciation Day to recognize those in our community that make a difference in the lives of individuals with autism. To nominate someone to be recognized, visit www.ACTpositive.org for an application.

Monday April 19th at 7PM Stephen Shore speaks on "Life on and to the Right of the Autism

Spectrum" at Kachmann Auditorium in Lutheran Hospital. Pre-registration is strongly encouraged.

First Annual
"WALK TO TALK"

Saturday April 24th, the First Annual "Walk to Talk". This fundraiser will go towards summer programming for individuals with autism. The walk will take place on the beautiful grounds of Saint Francis University in Fort Wayne. A pre-walk dinner will be held on

Friday April 25th.

Say "CHEESE!" It's Pizza Hut Time. Fort Wayne Pizza Hut has generously offered the Autism Community a portion of its profits on the following dates and locations:



Pine Valley Pizza Hut, TBA

Tuesday April 27th at the Decatur, IN location. Sales on delivery as well as dine-in service will benefit autism in Northeast Indiana. To receive credit, however, tickets must be presented. To obtain tickets visit www.ACTpositive.org or call (260) 609-7412.

Training Opportunities

In an effort to ensure our community has the quantity and quality of personnel to address the needs of the autism community in Northeast Indiana, ACT has raised funding to sponsor individuals to learn more about autism. Our aspiration is to inspire individuals to pursue careers working with individuals with autism. Due to the funding available through IN*Source and Indiana's Governor's Planning Council, sponsorships are not available for parents of children with autism spectrum disorder. Individuals selected for autism-specific education sponsorship will be expected to provide free service commensurate to the sponsorship level to a family in Northeast Indiana utilizing the skills acquired in the sponsored training. This program is made possible from a generous contribution from the Time Corner's Lions Club.

Applicants may apply for sponsorship to reputable autism-related training of their choice.



LECTURES

April 19th	Stephan Shore Life on and to the Right of the Autism
May 10th	Dr. Pratt on Managing Behavioral Challenges

All lectures are at Lutheran Hospital's Kachmann Auditorium and start at 7PM

WORKSHOPS

TBA	Faith and Disabilities
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All workshops are at Lutheran Hospital adjacent to the Cafeteria and start at 7PM.

SEMINAR *

March 5th	Take Your Knowledge of Autism to the Next Level
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This seminar will be at the University of Saint Francis Department of Education

*** Advanced registration required**

Indiana Autism Coalition Board

To ensure that issues relating to autism on a state level are coordinated and advanced, leaders in the autism community have formed a Coalition. The Coalition with offices in the State House will have

representatives from all over Indiana. Northeast Indiana will be presented by Paul Kraft and David Treman. A big part of the role of this entity will revolve around lobbying and advocacy at the state level.

My Story by Ritamarie Meyer

“Hello. My name is Ritamarie Meyer, and I have Asperger’s Syndrome.” That’s not how I introduce myself, but sometimes it’s tempting. It just seems like I should warn people that they shouldn’t expect me to be “normal”.

I was just diagnosed with Asperger’s this past April, at the age of 42. Of course my family and I knew I was “different” long before that; my mother says she knew it by the time I was two years old. We just didn’t know what my difference was called. Naturally the result was a lifetime of misunderstanding by many people, but fortunately, I had even more people who saw my strengths and helped me build on them.

One person who has helped me build on my strengths is also the person who started me on the road to diagnosis. A special education professor who I met in July, 2001, when I was taking a practicum. Throughout the six weeks of the course, she saw me do some wonderful things working with children, but neglect my paperwork and just generally “not fit the mold” for a traditional teaching situation. The criteria for the course are very much geared toward “Will this person be a good teacher in a school system?” A thirty-plus years of experience as a special ed teacher in several systems told my professor that I would NOT be successful in a school system. That same experience gave her a knowledge of autism that enabled her to recognize a pattern to my symptoms that others had not. I got a “D” in the course and a suggestion to read up on Asperger’s Syndrome. The best thing I got out of the course, though, was a friend. A friend who fought back her own tears as I sat blubbering in her office about my need for a new job, and if I couldn’t be a teacher, what would I do? A friend who reminded me of my strengths by asking for help on projects that she knew I would do well, and recommended me to others who needed someone with my talents. A friend who has asked me to speak to her classes about my life with a functional difference that no one understood, how they as teachers will have such students, and how they can help those children. When I speak to the university classes, I tell them how various teachers saw the same behaviors from me, but used different labels to explain them. Some saw a daydreamer where others saw creativity. Some saw a loner where others saw a leader. While most saw a smart little girl, my fifth grade teacher felt that my weak social skills indicated mental retardation! I didn’t know she had said that to my parents until I was an adult, but I knew she didn’t like me. Even so, I managed about a “B” average in her class.

Labels from doctors are another issue. Through out childhood, no medical doctor could come up with a label for me. Most just told my parents that whatever my problem was, I would outgrow it. After the remark by my fifth grade teacher, my parents had me tested by a child psychologist. They knew the teacher was wrong about my intelligence, but figured the fact that she would say such a thing meant I needed some sort of help. This doc-

tor said I was very smart, but didn’t come up with any other diagnosis. By my mid-twenties, I was diagnosed with sinus allergies and a spastic colon, but the doctors saw no connection to my mental issues, other than stress being an aggravating factor in the colon problem. At 30 I was diagnosed with major (biochemical) depression. A few years later Attention Deficit Disorder was added to the list. I would eventually learn that all of these have many of the same symptoms as Asperger’s, or may coexist with it.

Another thing I tell the university students is what I have achieved in my life. In high school, the journalism teacher saw this and my leadership skills clearly enough to make me yearbook editor my senior year. I won a small scholarship to the I. U. School of Journalism, and earned a bachelor’s degree there. I didn’t pursue that field professionally however, because I felt that God wanted me to be a nun. I did join a convent, but left. My poor social skills and depression were factors in my exit from religious life. I enrolled at St. Francis to study elementary education and earned the equivalent of a second bachelor’s degree. I worked at the Benet Learning Center until it closed in 1995. In 2000 I was admitted to the USF Master’s in Special Education program, and had a B+ average until I took the practicum. Ah, that practicum! I’ve lost count of how many times Susan has told me she wishes our friendship could have had a different start. But I know how essential that class experience was to my ultimate diagnosis.

Even without the practicum, I was having a very stressful summer, being between jobs. I was on medicine for the depression and ADD, but was developing a tolerance to the antidepressant. In short, my lowest point in almost a decade. The fact that she also saw my positive potential says much about why we became friends. If she had seen me in a better state, maybe the possibility of Asperger’s wouldn’t have occurred to her. Even if it had, if I had been able to earn a “C” or better in the class, I would have felt I was “close enough to normal” that I didn’t need to investigate a new diagnosis. I finally determined that I do indeed have Asperger’s in late 2002.

At this stage of my life, I am looking at possibilities. I have three tutoring students, including a little boy with autism. I work part time at a small law firm. I volunteer at St. Francis. Thanks to a special cheerleader friend and a change in medication, my depression is “in remission”. I’m looking into becoming a psychologist, specializing in the testing area. I’ll have to get a PhD for that, and first need to determine whether it would be best to finish my master’s in special education, or switch to psychology on the master’s level. And I’m writing. That doesn’t sound like such a big deal until I point out that I “lost” that skill in my mid-twenties, and just “found” it again a year ago. Maybe someday I’ll be a famous author! Only God knows. Whatever I accomplish in the future, it will be because of the unique combination of talents He gave me, along with the fabulous support of family and friends.



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

ACT Autism Community Together of Northeast Indiana

ACT's role is to engage and support individuals, families, medical professionals, therapists and educators with effective methods to improve the lives of individuals with autism and their families in Northeast Indiana. By focusing on 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.

Thank YOU!

Where would ACT be today without the generosity of those who helped it assert its agenda?

Thanks to News Channel 15 for their production and airing of the "Don't Wait, A.C.T." public service announcement promoting red flags indicating autism.



Thank you to the Time Corners Lions Club for its support of our educational initiatives such as the March 5, 2004 Seminar and Training Sponsorship Program.

Thank you to WOWO, News Talk 1190 AM, for supporting ACT in its 2003 Penny Pitch campaign.

Autism Advocates of Indiana for their grant to support autism awareness in Northeast Indiana.



The generosity of this community is amazing!

Concerned About a Child?

Everyone impacted by autism at one time or another reflects on "Shoulda, Woulda. Coulda's" - I should have recognized the signs of autism, if I just would have not denied the problem, if I just could have intervened earlier. No one disputes that early and accurate diagnosis is critical to long-term outcomes.

According to the National Alliance for Autism Research found that 35% of the public receives information about autism from TV programs compared to just 3% receiving it from doctors" Therefore, we have partnered with NewsChannel 15 to run awareness announcements setting forth red flags of atypical

development. This year thanks to a grant from Autism Advocates of Indiana we will be expanding our "Concerned About a Child" campaign with printed matter detailing red flags and local resources. Information will be downloadable from our website or by calling (260) 609-7412.