

Spring 2001

News and Views, Spring 2001

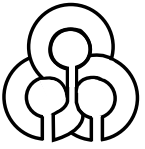
West Virginia Autism Training Center

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The West Virginia Autism Training Center at Marshall University

news and views

Huntington, WV • Spring 2001

From the Director

Barbara Becker-Cottrill, Ed.D.

Greetings to our registered families, educators and related personnel, colleagues and community members. It has been a busy time for everyone in the field of autism. As many of you know, Congress approved the Children's Health Act which among many things, includes a significant amount of funding through the National Institutes of Health for research concerning autism. There is also new funding through the Centers for Disease Control for epidemiology work in autism. The opportunities afforded through this new legislation have been made possible through the diligent efforts of families. A strong collaboration of parents, professionals, community members and legislators has been established nationwide and has opened doors to much needed research. Hard work lies ahead to understand, treat and hopefully prevent

this syndrome.

I am pleased to announce that our Center has received additional funding which will enable us to serve more families (see related article) and contribute to the epidemiological literature related to autism. The support of West Virginia Senator Robert C. Byrd made this and previous federal allocations possible and we are thankful that Senator Byrd has a true interest in not only autism but it's effects on families.

We are excited about the opportunity to expand our services. The Family Focus Positive Behavior Support Model is a comprehensive and individualized team training approach offered to our registered families and will now be available to additional families. We have established a model preschool program and will begin replicating the model this coming Fall.

There are many new projects in the works! With the talented group of staff members we have, we are poised to continue to develop quality training which leads to exciting outcomes for people with autism.

In closing, I encourage everyone to contribute something for autism awareness month this April. Call us to receive informational brochures to distribute in your community. Talk to others about the strengths and needs of someone you know with autism. Get the community involved in the life of someone with autism. Come to the Hearts for Autism Benefit Concert on April 30th at 6:30 pm at the Joan C. Edwards Performing Arts Center at Marshall University and enjoy the music of the Two of Hearts. Whatever you can do, you will be joining in the collaboration to provide a better today and brighter tomorrow for people with autism.

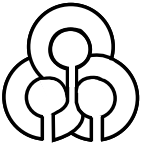
Autism Training Center Receives One Million in Funding From the Centers For Disease Control and Prevention

The West Virginia Autism Training Center (ATC) at Marshall University will receive one million dollars in funding from the Centers for Disease Control and Prevention beginning September 1, 2001. This is an additional \$313,000 above the previous year's funding. The additional funds will be used to serve more families by adding more trainers to the training staff. Each year approximately 75 new families register for the education and training services provided by the center. Once they are registered, they can access services for life. So each year, the number of registered families continues to grow. The additional funds will enable the center to continue to offer Family Focus Positive Behavior Support Training for those who request it, particularly for newly registered families. Early intervention is critical in

(continued on page 2)



Dr. Barbara Becker-Cottrill thanks West Virginia Senator Robert C. Byrd for his continuing support of the work of the WV Autism Training Center



**AUTISM
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One Million in Funding

(continued from page 1)

the prevention of more serious difficulties later in life. Young children with autism can learn a great deal if given the right educational supports.

The Family Focus Positive Behavior Support model uses a team approach. This program results in a highly individualized support plan for the person with autism. Members of the child’s team are trained in the implementing of each component of the plan. Assessment, plan development and implementation training lasts about six months with six months of followup. All training is provided in the child’s community.

The Family Focus Positive Behavior Support Model was developed and implemented by the ATC through previous funding from the Centers for Disease Control and Prevention. West Virginia Senator Robert C. Byrd’s support has been

instrumental in the development of this state-of-the-art service delivery model. His continuing support makes it possible for more families to receive this training. ☺

**For Current Training Opportunities
in Autism
in West Virginia**

**Check our Web Site at
www.marshall.edu/coe/atc**

Circle of Friends Preschool Program Opens

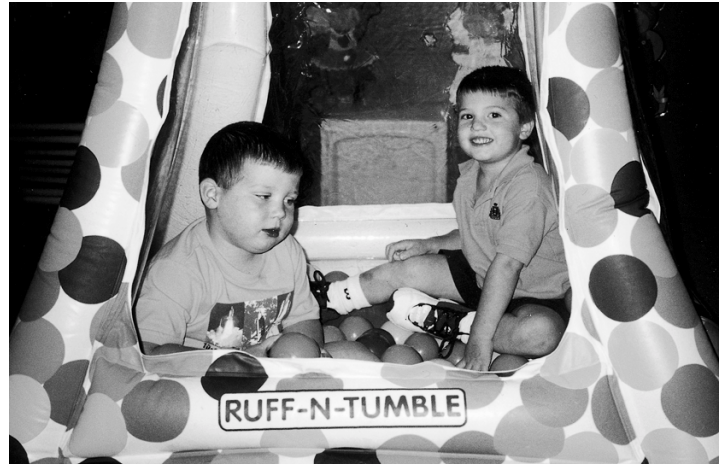
by Cindy LeGrand

“It is truly amazing what has been accomplished in such a short time. You have a very talented group of staff, and the enthusiasm and positive energy of both the positive behavior supports program and Circle of Friends was quite inspiring”

The Circle of Friends Preschool is a new program designed to serve three and four-year-old children with autism and their typically developing peers. This program is a partnership between the Autism Training Center at Marshall University, Cabell County Schools and the YMCA. The structure of the classroom and the methods of teaching are from research-based best practices in the field of autism and early childhood development.

The goal is to meet the developmental learning needs of all of our students by providing a fun, child-oriented environment with warm, caring and well-trained staff that will ensure high levels of child engagement. Incidental teaching is the primary instructional technique used throughout each day. Other instructional methods such as discrete trial teaching also are used as dictated by the individual children’s needs.

The Circle of Friends Preschool program depends on family participation. Circle of Friends staff members want to ensure that efforts at home and school are coordinated to enhance each child’s learning potential. The staff uses positive behavior support methods, team meetings and frequent communication between home and school to accomplish its goals. Positive behavior support incorporates a comprehensive set of procedures and support strategies that are selectively employed based



on an individual’s needs, characteristics and preferences.

The program is based on a comprehensive early intervention model established by Dr. Gail McGee, director of the Walden Early Learning Center at Emory University in Atlanta. Research shows that children with autism who attended the Walden Program — even toddlers — have shown drastic verbal improvements.

McGee visited the preschool last fall and was highly complimentary of what she saw. “It is truly amazing what has been accomplished at Circle of Friends in such a short time,” McGee wrote in a letter to Becker-Cottrill. “You have a very talented group of staff, and the enthusiasm and positive energy of both the positive behavior supports program and Circle of Friends was quite inspiring.” ☺

RESEARCH BRIEF: AUTISM SPECTRUM DISORDER PREVALENCE ESTIMATES

May Nawal Lutfiyya, Ph.D., Barbara Becker-Cottrill, Ed.D., Jennifer McFarland, Ph.D., Jennifer Zinn, M.A. Student, Shelly Arbogast, M.A., AND Bevin Kiser, M.A. Student

This research is supported by a grant from the Centers for Disease Control and Prevention.

All comments and inquiries should be directed to the first author at: THE AUTISM TRAINING CENTER, MARSHALL UNIVERSITY, HUNTINGTON, WEST VIRGINIA, 25705. email: lutfiyya@marshall.edu, voice: (304) 696-2831.

Although first identified in 1943 by Leo Kanner, the etiology of autism and the associated spectrum disorders remain unknown. Further, the prevalence of these spectrum disorders remain a question (Fombonne, 1996, 1999; Wing, 1993; Gillberg and Wing, 1999). Currently, there is an impression that the prevalence of autism spectrum disorders (ASD) is rising (Wing, 1997). While popular news literature and media lay claim to an alarming rise in prevalence, more academic and research-based studies and reviews argue multiple interpretations as to which direction the evidence points (Charman, 1999). Some researchers (Bryson and Smith, 1998; Gilberg, 1998) argue that the perceived prevalence increase can be attributed to more accurately identifying autism spectrum disorders. Other researchers (Fombonne, 1998; Fombonne, et al., 1997) maintain that the prevalence for the most tightly defined autism nuclear disorder (ND) remains unchanged at 5 per 10,000 while the prevalence of PDD is higher than an estimated 18 per 10,000. Needless to say, with the diagnostic criteria of autism spectrum disorders continually evolving and awareness of the disorders ever increasing, no easy or definitive answers will any time soon set aside the ongoing debate about prevalence. Literature spanning thirty-some years (1966-2000) presents autism prevalence rates ranging from .77 to 40 per 10,000 and ASD prevalence rates ranging from 5.25 to 67.45 per 10,000. One of the surest conclusions one can draw from these rates is that: "more studies are needed to evaluate the accuracy of these estimates" (Wing, 1997:1762).

Epidemiologically, prevalence rates describe the burden of illness in a population by providing an estimate of the probability of having a health status outcome or event at a given time. Among other things, prevalence estimates are used to make informed assessments about the impact of a health outcome on healthcare

and other system resources. In the case of autism spectrum disorders, accurate prevalence rates are needed to assist in the allocation of special education and other resources (medical, training, etc.) needed to address the secondary conditions of the disorder(s).

The research being conducted at the Autism Training Center at Marshall University contributes to the prevalence conversation. This research brief reports the findings from a recently conducted autism spectrum disorder prevalence study focusing on children aged 3-21 years. As analyzed and presented, these prevalence data provide baseline prevalence rates for tracking trends over time, as well as, for comparison to rates derived from other studies.

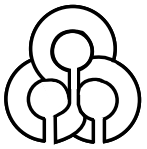
Using a triangulated data generation and analysis methodology, multiple data sources were consulted and unique cases combined in order to calculate population-based estimates. DSM IV criteria were used for case definition. The entire spectrum of autistic disorders were included in the investigation and prevalence rates were estimated for both the nuclear disorder of autism (ND) as well as the full spectrum of disorders (ASD). For children aged 3-21 the ASD and ND prevalence estimates were 21.12 and 12.06 per 10,000 respectively. By differing age groups, analyzed data yield an ASD prevalence rate of 20.52 and a ND prevalence rate of 11.64 per 10,000 children aged 3-5 years; an ASD prevalence rate of 30.07 and a ND prevalence rate of 14.12 per 10,000 children aged 6-10 years; and an ASD prevalence rate of 32.70 and a ND prevalence rate of 11.86 per 10,000 children aged 11-17 years. Finally, the data indicate that the oldest children, those aged 18-21 years, have an ASD prevalence estimate of 15.09 and a ND prevalence estimate of 11.86 per 10,000.

These are preliminary prevalence estimates that also serve as baseline data for future comparative examinations.

While these data appear to yield higher estimates than some studies, they are also lower estimates than others. Given the range of research methods used in different studies and the evolving diagnostic criteria employed by clinicians and others in ascertaining cases of all of the spectrum disorders, it would be a mistake at this time to draw the conclusion that the prevalence of autism and related disorders is increasing. ☺

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Using Task Interspersal to Teach Skills at Home

by Kim Ramsey

A great deal of attention is focused on selecting IEP goals and determining how new skills will be taught at school. Individuals with autism also benefit from a home curriculum developed to practice skills that occur naturally in the home environment. Aside from the obvious advantage of increasing the child's self-help skills and independence, parents also benefit when their children learn to become more self-sufficient. An added benefit for the child is the increased self-esteem gained from helping out at home and praise received for a job well done.

Task interspersal can be effective for assisting the child in completing non-preferred activities. Dick's parents are teaching him to sort silverware and put on his shoes. These are both non-preferred activities and Dick typically tries to avoid them. Dick does, however enjoy drinking juice, eating sandwiches and playing on the swings. Using task

interspersal, Dick's parents might begin by giving Dick a drink having him sort silverware, eat a sandwich, put on his shoes and then go play on the swings.

It is best to begin by teaching simple tasks that can be completed and mastered quickly. Some examples may include putting toys away, matching socks and sorting silverware. Remember to keep directions short and simple. Allow up to 10 seconds, if necessary, for your child to process the information. If necessary, provide additional prompting, but only the amount needed for the task to be completed successfully. As your child becomes more successful, gradually move away and decrease the level of support you provide. Finally, and most importantly, remember to generously reward your child and give yourself a pat on the back for being an effective teacher! ☺

Zachary Parties by Richard Covert

“Zachary and his pals have learned a tremendous amount from each other”

At the WV Spring Autism Conference, my wife and I attended a session by Professor Ann Turnbull, from the University of Kansas. She explained how she had developed a socialization program to help her autistic son. The program solicited the help of a college fraternity, which invited her son to their parties. As a result of the parties, her son found a group of peers that socially accepted him and became his friend.

After learning about the socialization plan that Mrs. Turnbull had developed for her son, my wife and I decided to have similar parties for our fourteen-year-old, autistic son, Zachary.

Like Mrs. Turnbull, we formed a team of adults to “brainstorm” and establish goals to improve Zachary's social skills. The team is made up of Linda and Richard Covert, parents; Sue Turnbull, Boone County Autism Itinerant Teacher; David McCallum, musician and social studies teacher; and Paulette Cooper, speech and language pathologist. The team developed a plan that incorporated age-appropriate peers to help increase Zachary's social skills through a series of theme parties called “Zachary Parties.” The parties lasted approximately two hours and are jammed packed with fun, food, music, games and activities. The team taught Zachary and his peers to interact with each other.

Then we invited eight of Zachary's classmates to the first “Zachary Party.” The party was a “huge”



Zachary and his pals

success. Since then we have had more theme parties ranging from a “Hippie Party”, a “Halloween Party”, “a Pizza Party”, and an “Ice Cream Party.” After the parties, Zachary's pals have made these comments: “Boy this was fun!” “Everyone will want to come to Zach's Parties” and “Zachary's parties are important to us.”

Zachary and his pals have learned a tremendous amount from each other, and when you mention his pals, Zachary will give you a “GIANT SMILE”. Zachary's “Party Pals” in the pictures are Damon Bias, Amber Chafin, Emily Harless, John Howard, Amelia Jarrell, Whitney Peters, Josh Turnbull, and Jose Vasquez. ☺

P.S. There are more Zachary Parties to come....

Spring Activity Workshop by Angela Patnaik

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Spring 2001

Last spring, the Autism Training Center provided an activity workshop for registered clients 14 and older. The workshop was held from February 18 to March 19 on each Saturday from 1:00 - 3:00. The individuals participated in arts and crafts activities, which simulated a prevocational environment.

The participants worked on the following items: ironing T-shirt transfers, assembling origami mobiles and assembling circle of friend's pins. Our volunteers were available for one-on-one assistance when required. Break time, provided every 30 minutes, allowed time for group socialization. The individuals who participated received monetary awards for each piece produced. They were given the choice of using the money for vending machines during breaks or to keep and spend it at another time.

The finished products were sold at the WV Autism Society Spring Conference in Charleston by one of the workshops participants. The response for our T-shirt design, created at the Center, was so overwhelming that we took orders. To

complete the orders for T-shirts, we held another workshop at Barbara Shiley's Autism classroom at Huntington High School. This workshop was held as an end of the year project for the classroom. All the students in the class participated in ironing the T-shirts and were rewarded with McDonald's gift certificates and an outing to lunch at the end of the school year.

Our many thanks go to Barbara Shiley for inspiring her class to participate in our project. Also, thanks go to all our wonderful participants and volunteers for a job well done and to the WV Autism Society for allowing us to sell our work products at the Conference. We thank you all for your support, diligence and creativity in making the Arts and Crafts Springs 2000 project a success. We are off and running with Activities Workshop 2001!

Some of the new products will be available at the Hearts for Autism Benefit Concert, April 30th at the Joan C. Edwards Performing Arts Center at Marshall University in Huntington. Call 1 (800) 344 5115 for more information. ☺

Josh's Big Day by Beth Kolopajlo

Joshua McAlpine enjoyed his 17th birthday party at ChiChi's on Saturday, September 30th. Seven boys from a local church youth group joined him in the celebration, as did his best friends Logan and Malo. It was Josh's first birthday party with friends in 10 years. He was truly excited.

For two weeks prior to his birthday, Josh made known his desire to attend Weir High School's Homecoming dance. (A dream that mom and dad had given up on several ago.) After several attempts to get a date and being rejected time and time again, Josh was becoming downhearted. However, 10 minutes before leaving for his party, Josh's mom received a phone call from a neighbor friend who had no knowledge of Josh's desire to go to Homecoming. The Kolopajlo's neighbor indicated that her 15 year old daughter, Jennifer, would be honored to escort Josh to his Homecoming if he was interested. Needless to say, the offer was excitedly accepted by Josh.

After a full week of anticipation, Josh's big day finally arrived. When he woke up the morning of the dance, he was on "Cloud

9" and couldn't wait to pick up Jennifer's flowers and get ready. His behavior was tremendous! His conversations with his date were very, very appropriate (and funny), something mom will remember forever. He was the perfect gentleman...opening and closing the doors (including the car door) for Jennifer. What training! And oh, how handsome he looked in that new suit and tie!

Josh and Jennifer ate dinner at Damon's. They arrived at the dance at 8 p.m. After a few dances, the couple had their picture taken. At 9:30, when Josh became bored and decided he wanted to go home, mom and dad were called to the rescue. Upon driving Jennifer home Josh, without prompting, asked permission to walk Jennifer to her door and even tried to arrange a date for his Senior prom in two years!

It was truly a night to be remembered. God truly works in mysterious ways. Never give up hope! ☺

HEARTS FOR AUTISM BENEFIT CONCERT



MONDAY, APRIL 30th at 6:30
pm

The Joan C. Edwards
Performing Arts Center
Marshall University

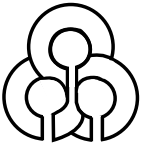
Featuring
THE TWO OF HEARTS

Tickets \$25.00 or 2 for \$40.00

Proceeds will go to the
Autism Training Center
Foundation for a lending
library of books and
educational video tapes on
autism for families throughout
West Virginia

For Ticket Information call 1
800 344 5115

Have a heart for autism !



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UNLOCKING AUTISM

Thanks to Beth Kolopajlo for this information

A nonprofit group, UNLOCKING AUTISM, has been founded and everyone's help is needed to spread the word about the first nationwide awareness project, OPEN YOUR EYES.

THE MISSION OF UNLOCKING AUTISM IS:

- To bring the issues of Autistic Spectrum Disorders from individual homes to the forefront of national dialogue.
- To join parents and professionals in one concerted effort to fight for these children that cannot lift their voices to the country for help.
- To educate parents about existing and pending legislation.
- To assist parents of newly diagnosed children by providing a clearinghouse of information, direction and a support network in an effort to decrease the amount of time parents need to spend researching this diagnosis, so they can focus on the needs of their child.
- To raise funds for both biochemical treatments and behavioral research.

Our first national goal is to collect 58,000 photographs of children with an autistic spectrum disorder. A million eyes will say a million words, allowing these children to ask the whole country for help. The boards were unveiled for the first time at an awareness rally in Washington, DC in April 2000. The pictures are arranged on boards as a monument to our children. The photos will be available to individual states after they debut in Washington for local awareness campaigns and education.

We are asking for actual photographs of your child, not electronic pictures sent via email. A registration form (see below) needs to be included with your photograph. Please rest assured that unless you indicate otherwise, the photograph will not be used for any other purpose.

We want to increase awareness about autism. A project like this will allow parents and guardians of autistic children to participate regardless of the treatments and therapies that they choose for their child. It will allow everyone to focus on the most important things we must fight for which are these beautiful children, many of whom cannot fight for themselves.

To obtain a copy of the registration form, call the Autism Training Center at 1(800) 344-5115, Monday through Friday from 8:00 a.m to 4:30 p.m. or go to the Unlocking Autism Website at www.unlockingautism.org

A project like this will allow parents and guardians of autistic children to participate regardless of the treatments and therapies that they choose for their child. It will allow everyone to focus on the most important things we must fight for which are these beautiful children, many of whom cannot fight for themselves.

Cycle USA

The Autism Society of America Foundation is raising autism awareness as well as funding for research through CYCLE USA. John Keating, father of a son with autism, will begin a three month bicycle ride across America. The start of his trip will be highlighted on NBC's Today Show on April 27th. West Virginian Bill Harvey, also the father of a son with autism, will accompany John on his journey. Cycle USA comes to Weirton, West Virginia on May 5th with a lunch hosted by Luann Decker. For more details on the Weirton event, contact Luann at John.Decker@prodigy.net. For more details on CYCLE USA go to the Autism Society of America web site at www.autism-society.org. Hats off to Bill and Luann and all West Virginians who are helping to make a difference !

**A Heartfelt
Thanks to Eric,
the owner and
Mike, the office
manager of
New Image
Computers.
Your support of
families with
autism is greatly
appreciated!**

DON'T MISS IT!!!!

Autism Society of West Virginia Conference 2001

April 6 and 7
West Virginia University
Morgantown, WV

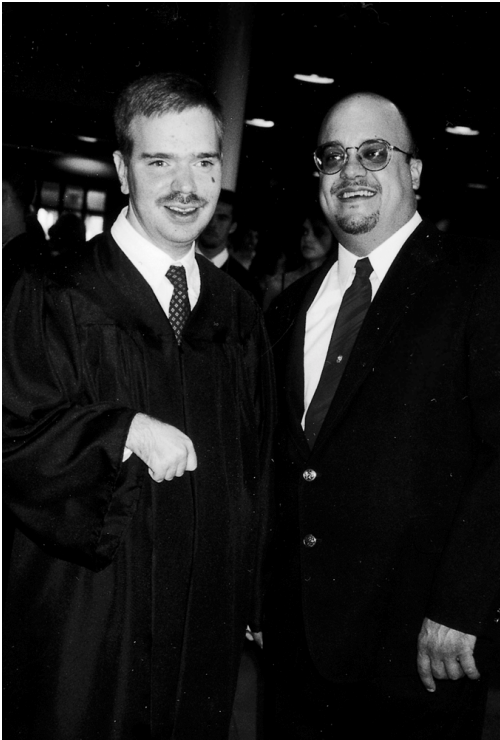
Conference Key Note Speakers:

Dr. Ami Klin, Yale Child Study Center.
Asperger's Syndrome: Practical Interventions for Parents and Educators
and
Dr. Nancy Minshew, University of Pittsburgh School of Medicine.
Understanding the Cognitive and Neural Basis of Autism: A Research Update

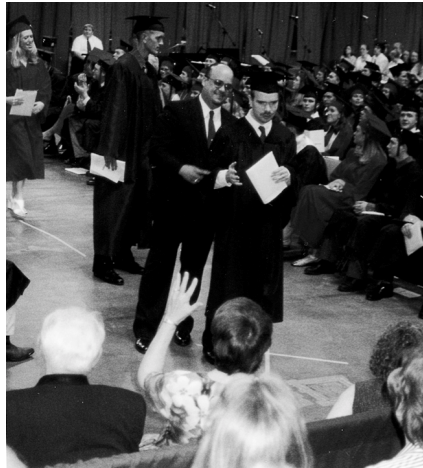
The Conference begins at 6pm on Friday, April 6th and from
8 am until 4pm on Saturday, April 7th.
Call 304-291-5772 to register by phone or to request additional information

Congratulations to Shawn Toney on Your Graduation!

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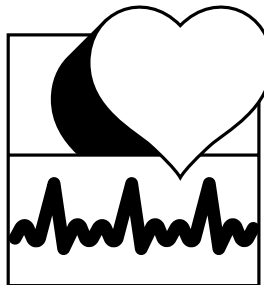
Shawn Toney, a student in Kanahwa County graduated last May with his class. Shawn is seen here attending his graduation ceremony. Everyone at ATC is so proud of Shawn. We look forward to a bright future for you!



"Shawn Toney and his teacher, Bob Costelac, at Graduation"

Got a Heart for Autism??

You can make a contribution that would help families who have children with autism by reaching them with information. Donations will be used to buy books and educational video tapes on autism. The Autism Training Center will mail them to families across the state.



Donations can be made out to the *Autism Training Center Foundation* and mailed to

The WV Autism Training Center
Autism Library
Room 316 Old Main
Marshall University
400 Hal Greer Blvd
Huntington, WV 25755

Mark Your Calendars for these Important Conferences!

2001 ABA Convention May 25-29, 2001

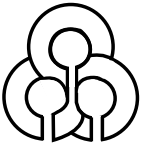
Hyatt Regency New Orleans
at Louisiana Superdome Poydras
at Loyola Avenue
New Orleans
Reservations: 504-561-1234

Autism Society of America Millennium of Hope

National Conference on Autism
July 18-22, 2001
Town and Country
Resort & Convention Center
San Diego, California
For Information: 301-657-0881
<http://www.autism-society.org>

Kentucky Autism Training Center Autism Institute 2001

June 28-30, 2001
Galt House Hotel
Louisville, Kentucky
502-852-4631
<http://www.louisville.edu/medschool/KATC>



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"When Your Child Becomes an Adult" Guardianship, Yes or No?

by Angela Patnaik

Turning 18 is an exciting time for many teenagers. Becoming independent and being legally able to enter into a contract, vote and marry are natural phases of life that most parents look forward to when their child becomes an adult.

However, when the child becoming an adult has a disability, the parent must make a decision that will alter their lives and the lives of their child. It is called being legally responsible for their adult/child (guardianship). According to Black's Law Dictionary a guardian is a person lawfully invested with the power and charged with the duty of taking care of the person, who, for defect of age, understanding or self control, is considered incapable of administering his own affairs. A parent may also consider becoming a conservator of their child's income, which would allow the parent to manage the business affairs or property of their adult/child. A parent can be a guardian but not necessarily a conservator. Or the parent may be both. To accomplish this, the parent must request the court's permission for both positions.

Here is how this process works. First, you must wait until your child turns 18. Since the hearing date may take two to three weeks, it would be safe to apply for guardianship two weeks prior to their 18th birthday. To obtain the application for guardianship, you must go to the circuit clerk's office and file a Guardian or Conservator Petition. In the application you must declare your child to be incapacitated, as well as his/her financial situation. You must also have a psychologist's report to assess your child's incapacity for self care. After this, a \$75.00 processing fee is required. The circuit clerk will set a court date and send notices to the child and anyone named in the petition, usually siblings and immediate family members.

In the second step the mental hygiene commissioner's office attorney will contact you for an interview with your child. Before the interview with my son, she asked me basic questions about my son's disability. She asked what his disability was, what level of care he could provide for himself and how he communicated. After I answered these questions, she interviewed my son. She asked him if he liked living at home, if he liked me, if he trusted me and was happy living at the house.

After the interview the attorney files a report based on her observation, interview with the child and psychologist's report. In my case, the hearing was scheduled 10 days after my son's 18th birthday and to avoid any legal situation in case of a medical emergency, I had his case manager complete a Determination of Incapacity form. This form was completed by his primary physician and ensured my legal rights in case my son had to go to the emergency room and I had to speak for him.

Guardianship

My son's attendance at the hearing was optional. I chose for him to attend. The Mental Hygiene Commissioner and his assistant presided. At the hearing the Mental Hygiene Commissioner met my son and explained to him what the hearing was about. My son shook his hand and he dismissed my son and continued the hearing with the rest of the family members named on the petition.

Family members introduced themselves to the Commissioner. Since I was the petitioner, I was the first person interviewed. I was asked the following questions. 1.

Did I believe my son's disability kept him from making decisions and managing his own self care? 2. Was I able to attend to his needs? 3. Could I budget his money and take care of his bills?

After I answered yes to each question, the Commissioner went around the room and had everyone introduce themselves. He asked the same questions to each person that he asked me. However, he asked an additional question to each family member. Do you believe Angela is the best person to address Vijay's needs? When everyone answered yes, the last question was asked. If I become incapacitated or died, who would become Vijay's guardian? In case of death or incapacity, the court would allow an addendum so that an immediate family member could apply and take custody in an emergency hearing. This would also be scheduled through the Mental Hygiene Commissioner's office.

It should be mentioned that anyone at the hearing can contest guardianship. However, the hearing usually goes smoothly. After the hearing I was required to purchase a guardianship budget for \$15.00 at the Circuit Clerk's office and keep an itemized budget of how much my son spent on living and personal expenses. I was told I must

According to Black's Law Dictionary a guardian is: A person lawfully invested with the power, and charged with the duty, of taking care of the person, who, for defect of age, understanding or self control, is considered incapable of administering his own affairs.

Get Ready for Camp Gizmo!

July 22-26, 2001

Romney, WV

For Information

contact Sue Mullett

at 304/766-4718

1-800-779-8287 or

Kathy Knighton or

Ginger Huffman

at 304/558-2696

1-800-642-8541

It was that time of year again. The beginning of school is stressful for any family, but is even more so for those of us with special kids. I was both dreading and looking forward to this school year.

My six year-old son Micah has autism. He was entering kindergarten in a regular classroom this fall. He had been in preschool for three years and we prepared very carefully for this transition, but I still worried. Will my son show how bright he is? Or will the new teacher have no idea what my son can do? Do I need to write yet another list of both his strong points and those things that need more work? I would certainly do that, if only to prevent myself from panicking when the teacher is understandably too busy greeting new students and their parents to spend a half hour or so with me going over what I feel she need to know.

Several years ago when I first wrote a list explaining my son's strengths and needs (I refuse to say "weaknesses"), I wondered how it would be received. Would the teachers or therapists feel that I was stepping over the line into their territory? I learned very quickly that most adults working with a child who is "different" welcome any information that can be passed along. I haven't sensed any awkwardness as I hand over my list. In fact, the adults usually seem a bit relieved. After all, a non-verbal child can seem like a mystery to anyone who doesn't know him, and I feel that by pointing out certain things about my child I am eliminating at least some of the guesswork.

Micah and I worked very hard this summer getting ready. We did task after task, increasing the difficulty as he became more familiar with it. I can honestly say that there are things that he can do now that he couldn't do in the spring. I used "West Virginia's Instructional Goals and Objectives" (you can request a copy from your child's teacher) to help me decide what he needed to work on, but mainly I used common sense.

There are other potential obstacles this year that I hope I've prepared him for. For instance, because of his special diet he needs to take his lunch to school. A quick look at conventional lunch boxes showed me right away that they might be difficult



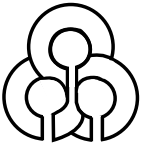
Micah

for him to open, so I bought one that closed with Velcro, which is very familiar to him. There is also a new type of drink bottle to contend with. His backpack needs to be full-sized. I went to a local flea market and had identification tags made for his lunch box and his backpack, and then tried to figure out how to introduce everything before the Big Day.

I decided that the best way might be to start using everything well before school starts. Micah has carried some of his favorite things in his backpack for several weeks and has been eating lunch out of his new lunchbox. His accessories may have a slightly used look but this is a small price to pay for him to know exactly what they are and feeling comfortable with them. I realize I may have overdone it and he might actually have adapted very well, but it seems to me there will be more than enough for him to deal with already. I don't want to take any chances that a small thing will impede him in any way, especially when it is completely avoidable. Parents of children with autism do a lot of planning and trial-and-error.

I hope that this year is Micah's best yet, and I am determined to do everything I can to realize that hope, but for now planning and a positive attitude are my main defenses. He is ready, whether I am or not, and I believe that this year will be a good one. ☺

After all, a non-verbal child can seem like a mystery to anyone who doesn't know him, and I feel that by pointing out certain things about my child I am helping to eliminate at least some of the guesswork.



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Guardianship, Yes or No?

(continued from page 8)

submit this to the court annually. Also, I was told I could pick up the guardianship papers in three days. Finally, I could legally speak for my adult son. I could continue to take care of him and ensure his rights would be met.

Many parents assume that because they have taken care of their adult/child for the first 18 years, they can legally continue to make decisions after the child turns 18 years old. This is simply untrue. The Court considers these children to be an adult and assumes they can be responsible for themselves. If they cannot, the State will assume the responsibility. To avoid this, I highly recommend all parents investigate their child's legal capacity before turning 18 and decide who should become their child's permanent caretaker. ☺

★ Congratulations to Drew Kiser!



Drew Kiser, Star Student

Drew Kiser attends Oak Hill Elementary School in Fayette County, West Virginia. Drew participated in the Family Focus Positive Behavior Support Model offered by the Autism Training Center. His Mom writes "Drew has made the outstanding honor roll for the past six weeks. We are very thrilled with this as you can imagine! Thought you would like to hear how well that positive behavior support training paid off!" We also understand that Drew continues to be a star student every month. Hats off to Drew! You're terrific!

For Joshua

On the first day of school
You walked through the door as the "Challenge" ...
Nothing could have prepared me for what I was about to experience
I questioned myself, Why Me?
How was I suppose to help him..teach him...guide him

Together, we succeeded...

I learned to reach you
In a way no other student could be reached
But I didn't do it on my own,
You allowed me to enter into your world of mystery
Bringing you intelligence and unforgettable personality to the surface

I watched you grow...

I used to sit and watch you
Listening to your silence
Wondering your thoughts and emotions
smiling and laughing
And in my heart I am so completely overwhelmed with joy
I know you are truly happy

You helped me grow...

Joshua...you are the reason for so many smiles,
The reason for why I teach,
And the single person that taught me
What it means to overcome a challenge and not be afraid

You will be a part of me forever...

You walked into my classroom
On that first day of school
As a mystery to be solved...
But on the last day you walked out of my class
As a unique child
Just like all the others
With humor, talents, strengths, and weaknesses
Most of all, you left that day
Leaving an impression forever engraved in my heart

Mrs. Veltri

Sean Barron is the co-author of There's a Boy in Here which was published in 1992. The book relates Sean's remarkable journey through autism and has sold over 30 thousand copies in the United States alone. Here is a short interview with Sean which provides a brief update on his life today.

B: At the end of There's a Boy in Here you were working in a nursing home as a rehabilitation therapist. What is your career like today?

Sean: It's gone in an entirely different direction. I'm writing for our local newspaper with an eye toward a journalism degree. It's happening at a snail's pace, however, as I work full-time at what is an extended internship. I started at the paper as a copy editor before they gave me general assignment reporting. Writing is what I've wanted to do for awhile and the longer I put off going back to Youngstown State University, the louder that inner voice seemed to resonate. Finally, I decided on my own that, despite caring greatly about the nursing home patients, I had to pursue this degree and get more immersed in the writing field. I think getting our book published gave me the notion that I could write. Besides, I can still

visit the patients with whom I worked and often do.

B: Since the publication of your book, you have traveled quite a bit doing speaking engagements. Is this enjoyable for you?

Sean: Yes, for several reasons - the biggest of which is giving something back to those who are struggling like we were. Writing our book has allowed me to purge myself of years of guilt for what I put others through. But I've also forgiven myself on a level that has enabled me to speak objectively about my experiences. In short, I have no more lingering regrets regarding my disability and behavior. As a result, I'm able to talk to parents and professionals about any aspect of what autism was like and similarly, I feel comfortable answering what people ask. In nine years of addressing audiences, I've never yet ducked any question anyone has asked me.

The traveling has been a bonus. I've gone places I never imagined myself going, like Iceland. Strange as it may sound, that European country was not on my Top 10 list of must-see places. What amazes me is that it's been nine years since our book hit the shelves and there's still a

certain demand for it. We're hoping to get it back in print to satisfy that demand. In addition, it's quite remarkable to be still getting requests to give presentations. I'll gladly keep giving talks on the subject as long as there's someone willing to listen.

B: If you had one message to give parents about autism, what would it be?

Sean: I think many autistic behaviors are ways of trying to communicate and make sense of what the child sees as a chaotic world. This was certainly true in my case. I also think it's so important to be flexible and not be afraid to try new things. I'm an avid jazz fan and improvisation is the lifeblood of that music. In much the same way, it's also critical in terms of dealing with children with autism.

Many children with autism have certain fixations. Parents can turn these into positives by using such opportunities for educational purposes. If, for example, a child is fixated on trains, take time to explain how a train works. Lord knows, I'm mechanically challenged and I'd love for someone (with or without autism) to explain to me how they work. I don't even know how the things stay on the track.

B: If you had one message to give to educators, what would it be?

Sean: I come back to that all-important word: flexibility. When dealing with something as diverse as a child with autism, it's so important to look at the whole picture, as should be done for anyone with special needs. Since most people with autism do well in structured environments, teachers can be sure the child's area of the room is set up in a manner conducive to his/her comfort. Also, since parents are professionals too, it's so important to keep open, unfettered communication between them and everyone else working with the child.

B: Thank you so much for sharing your insights!

Sean Barron can be reached through email at seanbarron@hotmail.com



Sean Barron

April is Autism Awareness Month!

Help teach others about autism. Call the WV Autism Training Center (1-800-344-5115) and request autism awareness brochures. Give them to everyone you know!



Have a Heart for Autism.

Come to the Hearts for Autism Benefit Concert

April 30, 2001

at the Joan C. Edwards

Performing Arts Center, Marshall University

Details inside!



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- Circle of Friends
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- Research Brief: Au-
tism Spectrum Disorder
Prevalence Estimate
- Guardianship, Yes or
No?
- An Interview with
Sean Barron
- And more!

