



Huntington, WV • Summer 2003

From the Director

Barbara Becker-Cottrill, Ed.D.

I extend greetings to all of our families, colleagues and friends and hope that you are all well. I want to begin with some well deserved commendations. First, I want to acknowledge the tremendous dedication and commitment of our current Family Focus Positive Behavior Support (FFPBS) team members. There are 46 active teams around the state and the outcomes they have facilitated for the individuals with autism they support has been inspiring. A brighter future for each individual with autism is the shared common goal, and together, piece by piece, step by step and goal by goal the future is indeed brighter for so many. Realizing that the right supports may change or need to be modified each and every year, many of our teams continue to be there for the individual with autism. And that is what it is all about. So I thank you for that commitment and I applaud your excellent work!

I also want to extend commendations to the educational staff of the WV Autism Training Center. The Educational Specialists, under the direction of Dr. Jennifer McFarland, have worked as a team to develop new improvements in the FFPBS intervention model. As well, their expertise as facilitators and their knowledge of educational strategies and autism has certainly brought about positive change for those they serve. Thank you for your dedication and your hard work with each and every family and team you serve.

None of the above would be possible without our office support staff under the supervision of Wanda Wells. If you spent a day in our offices you would see how hectic things can get and how they gracefully juggle all the balls in the air. Each and every person is devoted to the mission we serve. This fine staff is truly the foundation of our work.

Over the past few years, we have expanded our education and training work to include projects in the epidemiology of autism. With funding from the Centers for Disease Control and with the support of Senator Robert C. Byrd, we are working with several states that are conducting prevalence of autism studies. As well, the first United States legislatively mandated autism registry has opened and is housed and operated by the WV Autism Training Center. I am pleased to welcome Aniruddha Shinde as the epidemiologist who will oversee these programs. Aniruddha (Ani) comes to us from the University of Rhode Island where he completed his epidemiological studies.

I am proud to be a team member with this wonderful agency. Together, we are moving steadily ahead to provide the best possible services for our registered families and for those who work with individuals with autism in a variety of capacities. We are excited about our collaborative research projects as we strive together to make a difference in the lives of those we serve.

Senior Success!

By Jeannie Elkins

Parent and former ASWV (Autism Society of West Virginia) President

Recently an exit meeting was held that marked the end of our son Alan's 16 years in school. For us it was an occasion to celebrate and reflect on how Alan's quality of life and ours has



Alan Elkins

improved due to having an inclusive program with appropriate supports and services throughout his years in school. His remarkable journey from a very overwhelmed pre-school student to a confident, content senior prepared to graduate from Sherman High School has been more successful than we could have imagined possible. A few weeks ago he had a senior class picture made proudly wearing his "Proud to be Free in 2003" t-shirt. He has been educated in inclusive settings with the students he would have been with had he not had a disability.

As early as the 3rd grade his autism itinerant teacher began working on skills for transitioning him to Junior High. His transition was smooth and successful. We saw a significant improvement in Alan's self-confidence and self-management when he began a program of transition to work. In the seventh grade he began to work in the office at school and to train for some janitorial duties. In the 9th grade, through a program called "Building Bridges", he worked at a local library each afternoon. In the 10th grade, Alan began to work each afternoon at Boone Memorial Hospital in the laundry. This was from the beginning a job match made in heaven. He now also works one day each week in

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Autism Mentor training
July 21, 22, 28, 29
9 a.m. - 4 p.m.
each day at
The Marshall University
Graduate College
South Charleston
\$20. per day
Call the WV Autism
Training Center
to register
304/696-2332

Senior Success!

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central supply at the same job site. It is obvious to all who know him that he feels valued in a way he had not previously experienced. The first time I visited the Boone Memorial laundry and central supply job site I was thrilled to hear each employee tell me how much they depended on Alan and how impressed they were with his quality of and dedication to his work. After his first week on the job his job coach/ developer told me that he would be looking forward to having more students with autism participate in this program because of Alan's success on the job and his intense need to do the job perfectly.

The effectiveness of his program was made possible by the support of an extraordinary autism mentor, autism itinerant teachers, classroom teachers, administrators, job coach and the community support from Boone Memorial Hospital. This has prepared Alan at age 19 to have an enviable life and fulfilling job. He can contribute to the maximum extent possible for him. He has friends everywhere and still attends birthday

parties of longtime friends. As a family we cannot go out shopping, to a restaurant or movie without running into someone who knows Alan.



At his exit meeting the IEP Coordinator said she believes that our advocacy efforts for Alan's program have improved services for other children in Boone County. We attempted to express our gratitude to his team. How can we ever truly thank these extraordinary educators

who in so many ways, through extraordinary effort and vision, have given us back our dreams for happiness for our son?

Note:

This week we were notified by Boone Memorial Hospital Assistant Administrator, Mark Linville, that Alan will have a part time job in the Laundry and Central Supply Departments at BMH after he graduates. Transportation will be in place, thanks to the efforts of Mr. Mark Kennedy (Boone County Autism Itinerant Teacher) through a new community system that will be operational soon. This is a dream come true for Alan and for us!

Autism Training Center Welcomes Aniruddha Shinde, Epidemiologist

We are pleased to welcome Aniruddha Shinde to our staff. Mr. Shinde will oversee the surveillance of autism in West Virginia project and the Autism Spectrum Disorders Registry. He is a native of Bombay, India and a graduate of the University of Rhode Island. He recently received specialized training related to autism surveillance methodology at the Centers for Disease Control and Prevention. We look forward to our collaboration with Mr. Shinde as we work together to study the prevalence of autism and conduct other epidemiological work.



Walk for Autism in Huntington a Huge Success

Saturday, April 12th was a bright and sunny day for autism in Huntington. The second annual Walk For Autism, attended by approximately 300 people, took place at Ritter Park. The Walk was jointly sponsored by The Huntington Area Autism Society, The Autism Services Center and the WV Autism Training Center at Marshall University. Many sponsors and many volunteers made the Walk a great success. But, it was the coming together of the community and people with autism and their families that really made a wonderful impression. Marshall University First Lady, Pat Angel, spoke to that point in an opening talk about how much community support means to each family with a child with autism. After a brisk morning 5K walk, hotdogs were enjoyed by all.



Third Annual Walk for Autism

A collaboration between
the Huntington Area
Autism Society,
The WV Autism
Training Center
and the Autism
Services Center

**Saturday, May 1, 2004
Huntington Ritter Park**





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P.A.L.S./Peers Achieving Leadership Socially

By Amy Riley
Sutism Teacher, Cabell County Schools

As part of Character Education and integration among the regular education and special education students, P. A. L. S. was born. P.A.L.S. is a new program at Miller Elementary that matches students with and without disabilities for peer tutoring. Debbie Abel's (regular educator,) 5th grade students wrote a letter of interest about job openings for peer tutors in my classroom. Her students also filled out job applications, were interviewed for the positions, and signed contracts upon employment.

Mrs. Abel's students were assigned a work schedule and filled out time cards. They also have name badges they wear while working. It is a great learning tool for everyone involved.

P. A. L. S. participants give up their recess time to work on many different activities during their half hour sessions. Although social skills was the basis for the program, my students are getting just as much educational benefit. Some of the

educational activities the P. A. L. S. participants engage in are computer skills, phonics and reading skills, touch math, counting, time, fine and gross motor skills, writing, and spelling. P. A. L. S. participants also work on social skills such as rules of conversation, turn taking, and manners. P. A. L. S. participants have made great progress using positive behavior support by giving out stickers, candy, and tons of verbal praise. The tutors bring crafts from home and often

bring in their own worksheets and activities for my students that they have downloaded from the internet.

At the beginning of the school year we had 8 peer tutors signed up for our program. As of mid-year we now have 17 students volunteering their recess in my classroom. We are very proud of our program and the knowledge, patience, and understanding we have all gained!



DUKE UNIVERSITY MEDICAL CENTER RESEARCH TO FIND THE GENETIC FACTORS IN AUTISM AND ASPERGER DISORDER

Our research team is looking for families with *one person* (or more) under the age of 21 with Autism, Asperger Disorder, or PDD-NOS.

Participation is free of charge and no travel to Duke Medical Center is necessary. Study participation involves a family interview, several developmental interviews, and obtaining blood samples. These will all be completed by mail, telephone, or in person at your convenience.

Please contact the study patient coordinators, Shannon Donnelly or Leigh Elston at 800 283 4316 extension 1, or email center@chg.mc.duke.edu. Visit our website for more information at <http://www.chg.duke.edu>. **YOU CAN HELP MAKE A DIFFERENCE!!!**

School to Work

By Angela Bryson
Parent Support Coordinator

news and views
Summer 2003



The first step to transitioning from school to adult life is the written Individual Education Plan (IEP). The IEP begins with identifying goals developed by a multidisciplinary team that should include school and community professionals, and you and your child. The plan should identify services that will assist your child in living and working in the community successfully.

The transition process should address ways to facilitate overall adult adjustments by addressing educational and vocational programs with regard to your child's emotional, social and daily living needs.

The School to Work Program in WV has a vision for workforce development. Since 1999, beginning in the ninth grade, each high school student is required to have a work-based learning experience prior to graduation. The School to Work Office has developed guidelines for an integrated career development system that includes awareness in K-4, career exploration in grades 5-8, in-depth exploration in grades 9-10, and career preparation, decision making and applications in grades 11-graduation.

To begin, a job assessment needs to be completed. The value of an employee is determined by how well his/her skills and interests fill a void for the employer. The same theory applies to an individual with autism. Despite the problems with socialization, communication and challenging behavior associated with autism, each individual brings a unique combination of skills, interest and potential. Vocational planning for

workers with autism include determining the suitability for a particular job.

One of the ways this is implemented is through job shadowing. Students should have the opportunity to shadow a variety of jobs related to their specific interests. This will give the student the opportunity to make an educated decision as to whether or not a certain career is

something they may like to explore after graduating from high school.

Many counties throughout WV have a wonderful school-to-work program already in place.

Parents can play a major role by monitoring their child's progress in the work program. The information a parent can gain will provide valuable information when their child graduates in locating volunteer positions or gainful employment. Also, if the adult is connected to case management services through a behavioral health/mental health center, the case manager can provide valuable links to possible job sites. In addition, if the adult is on the MR/DD Waiver program, a community program manager can write programs to provide needed support in the workplace. This program provides a win-win situation for students with special needs.

From a personal perspective, my son is 19 years old and has been in the school to work program for the past 3 years. He has gained valuable experience in job shadowing different career opportunities and we have gained valuable information to know where he is the happiest. He has a position three times a week as a material handler. He enjoys his job. He enjoys the social opportunity that it provides and he also enjoys the paycheck he receives every month. He has a bank account, saves his money but likes to go bowling once a week with the money he has earned. He is proud of the job he is doing and so am I.

SAVE THE DATE!

The Autism Society of West Virginia Announces the Annual Spring Conference

Sponsored by:
The Huntington Area
Autism Society,
The Autism Services Center
and
The WV Autism
Training Center

April 16 and 17, 2004

The Radisson Hotel
Huntington, West Virginia

**Presenting a spectrum
of current topics
on autism
AND featuring
a full day workshop by
DR. TONY
ATTWOOD
World Renowned
Asperger's Syndrome
Expert**

For additional
information contact
WV Autism Training
Center at 304-696-2332



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The Kentucky Autism
Training Center Hosts
Autism Institute:
Strategies Series 2003

July 21-24
Spectrum Building
Auditorium,
Louisville, Kentucky

Featuring
Dr. Amy Wetherby
and Linda Burkhart

Promoting
Communication, Social
Skills and Cognitive
Development for Children
with Autism Spectrum
Disorders

*Visit the WV Autism
Training Center Website at
www.marshall.edu/coe/atc
for the registration form
and more information or
call us at 304/696-2332*

On Autism, Self-Awareness and Disability Education

By **Kent Moreno**
Educational Specialist Senior & Parent

Autism Spectrum Disorders(ASD) (Autism, Pervasive Developmental Disorder, Not Otherwise Specified (PDD-NOS) and Asperger's Syndrome) are complex disorders which dramatically effect an individual's ability to function in everyday life. Deficits in socialization are especially challenging as they make it very difficult for individuals with an ASD to integrate successfully with their peers and society in general. I believe there is a common misconception that because someone is autistic they lack self-awareness or deeper feelings. This is not the case. An individual may be withdrawn or aloof, but this does not mean they are immune from emotional pain or lack the ability to have insight into their lives. Over the years I have heard statements from individuals with Autism Spectrum Disorders (ASD) who function at a higher level or the parents of these individuals, pertaining to low self-esteem, depression or traumatic life experiences (teasing, academic failures, etc.) that are the result of challenges created by having this disorder.

A partial remedy to this situation is peer education about ASD, with understanding comes acceptance (usually). This is only part of the solution. What I never hear is how an individual with an ASD has been educated about their disability and its effects on their life. Most often when one meets a child with diabetes or asthma, that child knows all about their disorder. They know what they can do or can't do, they know alternative strategies for overcoming limitations, and the warning signs. I think, as parents and professionals, we are doing a significant disservice to individuals with ASD who have the intellectual ability to understand their disability if we neglect to educate them about that disability.

How important is it to educate individuals with autism about their disability? Temple Grandin and Sean Barron, both well known individuals with autism, have stated that becoming aware they had autism was a significant positive experience for them. Being aware they had autism meant that for the first time, they understood why certain parts of their lives were so difficult. Being educated about autism also gave them the knowledge necessary to find alternative strategies (e.g. using visual aides) which helped them to succeed where they had failed in the past. Lastly this awareness resulted in greater self-acceptance.

So how do we talk with a child who has an ASD? I would recommend starting to talk with the child as early as possible. As it can be difficult

to assess what a child diagnosed with an ASD understands, until you know otherwise, assume that every child with an ASD has the ability to understand what they are being told. A good way to start is by spending time with the child diagnosed with an ASD by reading childrens' books or watching age-appropriate movies which have individuals with autism as characters. When in the course of the story it's mentioned that one of the characters has autism, that's a good time to let the child know that they, just like the main character, have autism (or Asperger's...). I would repeat the process a number of times. If possible, use a variety of books or movies. Once the child has a name to go with the disorder, slowly start giving the child more information about their disability and how it effects their life.

Another way to introduce the disability would be to educate the individual about famous people in history who are suspected of having an ASD including; Albert Einstein, Thomas Jefferson, Wolfgang Amadeus Mozart and Vincent Van Gogh.

When talking with a child about having an ASD, it is important to be flexible. While it will be helpful to have a general idea of what you want to say to the child, nothing should be "written in stone." Rather, let the child, his or her needs, and their response to what you are saying, be your guide. It might be helpful to refer back to a book or movie in which the character with an ASD has problems similar to the ones experienced by the child and discuss options for overcoming the difficulty.

It's also very important that having an ASD is not presented in such a manner that it becomes an excuse for not doing or trying something. To do so allows autism to become a crutch and, over time, the individual will make less and less effort in the face of adversity.

Lastly, when talking with an individual with an ASD, don't forget to include the strengths that also accompany having an ASD including; excellent memory skills, strong visual learning skills, attention to detail, strong analytical ability, specific to general thinking skills and the ability to look at life from a different perspective.

Dr. Tony Attwood, a well known expert in the field of autism, refers to ASD as a brightly colored thread in the tapestry of human diversity. Hopefully by educating individuals with ASD's about their disability they will experience more and greater successes in life and, perhaps just as important, appreciate their role as one of the brightly colored threads in the tapestry of human diversity.

Your Child's Transition from Preschool to Kindergarten - A Plan for Success

By Gloria Sage, Educational Specialist Senior

By Cindy LeGrand, Coordinator, Circle of Friends Preschool

news and views

Summer 2003

Transitioning from a preschool program to kindergarten can often be stressful for both parents and children. Families may be concerned with the upcoming changes in relationships that have become so important in their daily lives, the changing expectations for their child, and just being bittersweet about their "baby" growing up and starting Kindergarten. Although sometimes stressful, transitions can and should be a comfortable and positive experience for the child, family and program staff.

How do we plan for a smooth transition from one program to the next?

The ideal transition should be a *"carefully planned, outcome-oriented process, initiated by the primary service provider, who establishes and implements a written, multi-agency service plan for each child moving to a new program"* (McNulty, 1989, p.159).

There is a variety of strategies that can help to create a positive and successful transition for children, families, and teachers. Strategies must be tailored to address a variety of services and meet the needs of individual children and families.

A written transition plan should be a part of each child's IEP. This should include specific activities, resources, and timelines for each activity. Along with the transition plan, an established means of communication among families, sending professionals and receiving professionals will help to facilitate the process. Opportunities for the transitioning child's parents to visit the kindergarten classroom might be part of the transition plan. Parents may want to visit the classroom on several different occasions and at different times of the day to observe a variety of activities.

The kindergarten teacher may want to visit the child in his preschool classroom before the end of his preschool year. This gives her an excellent opportunity to interact with the child in an environment he is comfortable and confident in. She can also observe him during his daily routines and may be able to suggest some activities for him to work on during the summer to prepare him for the kindergarten room. Of course, this is a perfect setting for the child to meet his new teacher, on his "own turf".

Having the child visit the kindergarten classroom before the end of the preschool year should also be part of the transition plan. Depending upon the child's personality and

developmental challenges, she may do best initially visiting the classroom when other students are not present. She would have an opportunity to explore the classroom and materials with her parents and the kindergarten teacher, without the intrusion of other students. Later, one or more visits when other students are present would give her a chance to see what kinds of activities she will be participating in next year. This would also be a good time to take pictures of the school, the classroom, and the teachers. These could be put in a small photo album to be looked at and talked about during the summer.

Parents may want to drive by the school and/ or visit the playground during the summer and talk about this being the child's new school. Another good summer activity would be to write a social story about the new class. This could describe what the new class will be like, what they will do there, and address any fears the child might have. Photographs of the classroom, the playground, and the teachers could be incorporated into the social story. Parents could read the social story to the child over the summer, and then start reading it to them daily about one to two weeks before school starts.

Another tool that can assist children with transition is a People Locator. A People Locator is a visual support that shows children where significant people are during the day. It is usually made from a piece of poster board divided into three sections, labeled HOME, SCHOOL, and WORK. Pictures of the child, family members, friends, and teachers are placed in the appropriate sections of the board to show the child where that person is. For example, if a child was concerned about where her mother is while she is at school, a picture of her mother would be placed in the section marked HOME (or WORK). The child's picture would be placed in the section marked SCHOOL, along with the teacher's picture and the classmates' pictures. Other persons' pictures could be placed in the appropriate sections. This tool can help to ease children's minds about where important people are.

Families and teachers may use one, several, or all of these strategies when planning transition activities from a preschool to a kindergarten classroom. The key is to have a plan and to start transition activities EARLY. Communication between the family, the preschool teacher and the kindergarten teacher is essential for success. With families and professionals working together, successful transitions can be assured.

"Communication between the family, preschool teacher and the Kindergarten teacher is essential for success"

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Employment Opportunities with the WV Autism Training Center

Positive Behavior Support Facilitator:

Facilitate and provide training for teams supporting individuals with autism.

Master's degree in Special Education or related field and experience preferred.

Abstractor (part-time)

Assist in record review and data collection as part of a national study of prevalence. Bachelor's degree in Special Education or related field.

Community Partner (part-time)

Provide support to families of persons with autism. Applicants must have a child with autism or other developmental disability and have a good knowledge of community resources.

To receive more information please call the WV Autism Training Center at 304-696-2332

Charting the Path to Adult Living

By **Kim Ramsey**
Program Coordinator Senior

Part I: Background

One of the most important decisions high school students make is determining the next step after graduation. Most adolescents are faced with major transitions at this point in their lives. The ultimate goal of transition planning should lead to successful functioning in adulthood. For individuals with disabilities and their families, options may be more limited and appear less clear.

All successful transitions involve careful planning for the future. One of the most important elements of transition planning revolves around early planning and preparation. The Individuals with Disabilities Education Act of 1997 (IDEA: P.L. 105-17) requires that schools begin transition planning for students at age 14. While this legislation provides important value, parents and their children should begin to think about life following high school much earlier. It is very important for individuals and their families to work closely with the school, and often adult service agencies, to consider appropriate transition options and to plan for the future.

Remember, no single transition plan is appropriate for all. Post-school options for individuals with disabilities vary greatly and depend upon a number of factors. Some of these factors include the individual's interests, abilities, and community. A common thread is the vital need for opportunities that will allow the individual to succeed and experience a sense of accomplishment in everyday life whether at home, at work, in school, or in the community. Careful consideration of these elements will lead to choices that ultimately determine personal fulfillment and quality of life.

When thinking about possible school to adulthood transition options for your child, consider these questions:

- What types of activities and tasks does my child enjoy?
- What are his strengths? What jobs require similar skills?
- What social and communication skills are required?
- What other skills are required in the workplace?
- How can these skills be taught?

Part II: Building Skills

Your adolescent or young adult child with autism is a unique individual. You have spent years loving, nurturing and supporting him. Parents often report that one of the most critical and often stressful times occur as their adolescent completes public school and transitions to adult life. Successful transitions involve careful planning for the future. While transitions can be difficult for the entire family, certain strategies can help ease uncertainty and prepare for the future.

One way to help prepare young adults for new settings is to get a head start on teaching skills that will help him function in the new environment. Selecting appropriate skills to teach may be the most important first step in preparing the young adult for a more independent life. Skills that are taught should be based on the individual's interests, abilities, and the context in which the skills will be used.

An important area of education for individuals with autism involves learning daily living skills. This broad area encompasses a number of complex skills that can be difficult to acquire. Parents and teachers often express surprise when their children and students are able to independently complete some very complex skills, but are unable to complete other more simple ones.

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Your Child's Transition . . .

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An Early Childhood Transition Checklist was developed by the WV Steering Transition Team to assist families and programs with planning and implementing appropriate transition activities. A copy is available by calling the WV Autism Training Center at 1-800-344-5115.

References

Hanson, Marci, (1999) Early Transitions for Children and Families. Eric Digest # E581

Policy 2525 WV's Universal Access to Early Education System

WV Early Childhood Transition Checklist

(continued from page 8)

A critical part of preparing individuals with autism for adulthood often requires specific training that teaches daily living skills. Sometimes, determining which skills to teach can be more challenging than teaching the skills.

Since individuals' interests and abilities vary greatly, selecting appropriate skills to teach requires an individualized approach. For example, if your child expresses an interest in washing dishes but has difficulty bathing, it may be helpful to identify some common elements that might be used to teach bathing. Would he prefer to bathe using a sponge rather than a washcloth? Or, could he practice washing dishes using a "scrunchy" instead of a dish cloth?

While the specific skills you decide to teach will depend on the individual's interests and abilities, there are general skill areas that are important for most individuals to learn. Most skills can be taught by breaking them down into small, manageable steps. At first, individuals should be prompted, if necessary, to successfully complete the task. Experiment to find ways to make learning fun and remember to reward him for a good effort!

A Sample Daily Living Skills Inventory is available at the Autism Training Center and includes a partial list of skills needed for independent living. Items are rated with (0) if the skill is **never** completed; (1) if the skill is **sometimes/partially** completed; and (2) if the skill is **always/usually** completed.

Before completing the checklist, you may need to modify the listed skills to more closely match your adult child's interests, abilities, and the environment(s) where he lives and/or works. Carefully consider the answers to the following questions:

- What tasks or activities does he like to do?
- What are the areas of strengths and needs?
- What are the essential skills that are needed in the environment where he lives and/or works?
- What types and how much support will be provided in the new setting?

Part III: Tips

Successful transitions from school to adulthood are based on assessment, planning, skill acquisition, support, and coordination. Commitment, collaboration and hard work are the key elements.

How can schools help prepare students for adulthood?

- Focus on teaching functional daily living skills within the curriculum.
- Assist students in developing self-advocacy and independent work skills.
- Conduct comprehensive assessments and train critical skills.
- Provide families with information regarding how to access adult services.

How can families help prepare their children for adulthood?

- Begin preparing your child for the demands of adulthood at an early age.
- Focus on teaching independent living skills.
- Be an active participant in the transition process.
- Advocate for your children.

How can students prepare for adulthood?

- Identify their personal interests and preferences.
- Actively participate in the transition process.
- Focus on learning essential skills.
- Self-advocate. Learn when, how and who to ask for help.

How can service providers assist with transitions?

- Clearly identify the agency's mission and acceptance criteria to schools, parents and individuals with disabilities.
- Provide schools, parents, and individuals with concise information about how to access services.
- Assist in the transition process.

news and views

Summer 2003



GOT A HEART FOR AUTISM?

You can make a contribution that would help families who have children with autism. Your monetary donation will be used to purchase books and educational videotapes on autism for the Autism Training Center lending library. This is a free service for registered families throughout the state of West Virginia.

Donations can be made to the "Marshall University Foundation for the Autism Training Center" and mailed to:

Autism Training Center
Marshall University
One John Marshall Drive
Huntington, WV
25755

**Eighth Annual
PATH Conference**
(Partnerships in Assistive
TechNologieS)
September 17 - 19, 2003

Charleston Civic Center
Charleston, West Virginia

1-800-779-8287

www.wvpaths.com

Training in the Picture Exchange
Communication System
will be offered as a part of this conference by
staff of WV Autism Training Center.



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“Karen is always willing to lend a helping hand when teamwork is needed and this reflects genuine dedication to the job.”

Karen Midkiff is Marshall University Employee of the Month

Karen Midkiff, receptionist in the West Virginia Autism Training Center, has been named the Marshall University Employee of the Month for February, according to Jim Stephens, chair of the Employee of the Month Committee.

An employee of Marshall for 2 years, she was nominated by Cheryl Beaver and Wanda Wells.

Wells, who is an administrative associate/ office manager for the center wrote, “Karen Midkiff is the first person visitors or callers talk with when contacting or visiting the West Virginia Autism Training Center at Marshall University. With her warm personality, she readily puts people at ease. She is always ready to go the extra mile for anyone who needs her help. She works with our staff, who are located across the state of West Virginia, as well as those in our offices here at Marshall University, coordinating their schedules, making appointments and rescheduling appointments for families as well as our staff. She does a great job of keeping these important duties on an even keel. Karen has a quiet presence but her friendliness and helpful demeanor do not go unnoticed. She works with client families in any

way she can, listening, dependable, always on the job early. We appreciate her very much.

Beaver, who is a secretary at the Autism Training Center, says, “Karen...is very dedicated to her job. She has excellent phone skills combined with a pleasant personality which makes a great first impression...She is conscientious about her job and every assignment she is given is handled with perfection. Karen is always willing to lend a helping hand when teamwork is needed and this reflects genuine dedication to the job. Professionalism is the key word to describe how Karen handles the pressures of hectic



phone lines, taking care of mail, and greeting visitors in our lobby. Karen knows how to locate staff, because she consistently updates their schedules on a day-to-day basis. She is always kind, generous and willing to help you with any questions you may have. The West Virginia Autism Training Center really appreciates her extra efforts and hard work!”

She was presented with a plaque, balloon bouquet and a check for \$100 by Lance West, Vice President for Alumni Affairs. She will be eligible for Employee of the Year.

Announcement of Fall Courses in Autism

The Introduction to Autism course **will be offered as a WebCT computer based course for the fall 2003 semester at Marshall University.** The course is not listed in the MU Fall 2003 schedule book. To register for this 3 credit hour class, you will need the following information:

	Undergraduate	Graduate
Subject:	CI	CI
Course:	427	527
CRN:	4678	4679
Section:	101	101

Class begins the week of August 25, 2003 through December 12, 2003.

For more information on this course, please call Cathy Jo Templeton at the Autism Training Center, Marshall University, Huntington WV 25755, Phone: 304-696-2332.

For registration information, you may call the Registrar’s Office, Phone 304-696-6413.

For admissions, call 1-800-642-3499.

Instructors for this course are Dr. Barbara Becker-Cottrill and Dr. Jennifer McFarland, Autism Training Center, Marshall University.

Blessings

By **Kent Moreno**

Educational Specialist Senior & Parent

While there are more than a few differences between parenting a child with a disability and a typical child, there's one difference of which I am particularly aware.

Megan, at age twelve, is pretty much your typical pre-adolescent. Spend a bit of time with her and you have a pretty good idea of the person inside the body. Additionally, while Megan has been the beneficiary of good teachers and other adults who have had a positive impact on her life, they somehow seem less crucial to her life than have the important adults in the life of my son, Ben, who is dually diagnosed with Down Syndrome and autism.

If Ben isn't extremely familiar with an individual, he can be very aloof and stand-offish. As a result, I worry that the people who meet Ben will only see his significant delays and differences and not the incredibly wonderful person who dwells within. In no uncertain terms, I want the people who come into Ben's life to be able to see beyond the superficial stuff and discover the person inside. Even more I want that person to experience the joy that our family does by having Ben in our lives and to know that their life, like ours, is somehow made better by knowing Ben.

When a person comes into Ben's life who sees Ben as a person, derives joy from being with him, develops a rapport with him, advocates on his behalf even if it means more work for them, and by their actions improves the quality of his life, I see that person as a huge blessing in Ben's life. And I feel a profound sense of gratitude towards that individual. To me, it is the perception of certain individuals in Ben's life as "blessings" which is the most prominent difference between having a child with a disability and a typical child.

One of my most treasured possessions is a letter written by one of those blessings in Ben's life, a former teacher:

"June 6, 2000 This has been a special school year and Ben has helped to make it so. He has become a friend and a part of the group. Most

of his classmates are more aware of the changes in him than in themselves. When I think of Ben in September, I recall he limited himself to a small portion of the room and seemed not to acknowledge us. Now, he "owns" the school and often doesn't mind being in the middle of lively activity. We miss him when he is absent and are pleased when he and Miss Cindy (his aide) are doing what we are doing. He has helped us to learn to be patient, to find pleasure in helping others, to recognize and value differences and to appreciate the successes of our friends. I hope what he may have learned from us is as valuable"

I'm pleased to say that Ben has had quite a few blessings in his life. While many of these blessings have been educators, there are also family members and Ben's pediatricians who fall into this elite category of special people.

With regard to educators, professionals working in the field of education average 6 years before changing careers. I want to encourage parents with special needs children who are reading this not to hesitate to let those people who are blessings in your child's life know how you feel about them and the role they played. In addition to the personal satisfaction experienced by the individual hearing your kind words, the long term effect may be that an exceptional professional in the field of education (or other field) stays where they are desperately needed rather than seeking different pastures.

For the professionals reading this, what we, as parents, want as much as your expertise, is your love and acceptance of our children. Go that extra mile for our children and you'll have our profound gratitude and a very special place in our hearts for many, many years to come.

"I want to encourage parents with special needs children. . .not to hesitate to let those people who are blessings in your child's life know how you feel about them..."



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To learn more about the
WVATC's
Family Focus
PBS Model see
[Focus on Autism and
Other Developmental
Disabilities Journal,](#)
Summer, 2003
Volume 18 (2)
Pages 112 -123

Reflections

By **Belinda Moore**
Community Partner & Parent

I think it is unique how having children is destined to change your life. However, there are some changes a child can bring to your life that are not normally expected.

Jenny was born in April, 1997. Jenny has accomplished a lot in her short time so far on this earth. Some things other parents take for granted and some things parents like me could never dream would happen, have happened. Jenny was our first child so there was a lot that we as her parents had to do, a lot of changes that had to take place. Jenny sat up at 4 months and began to crawl at 8 months. She didn't seem to want to walk. I say this because she would walk around furniture and if there was someone on both sides of her she would walk. The minute there was nothing to hold onto Jenny went down. The doctor told us not to worry, just give her some time. He was right. She soon began to walk.

The next obstacle was speech. A short while before Jenny began walking, she started participating in early intervention. Through early intervention, she started speech therapy. Jenny could say a few words like "ma" and "ba" but she mostly used jargon. It was obvious to us that something wasn't right, so we talked to the doctor and he again told us to give it time and we did. This time, however, there was no improvement. I could not just sit back and wait, so I started doing my own research and I ended up with the same word every time, "AUTISM". I did not want to believe it could be autism. I thought maybe she had apraxia or sensory integration dysfunction but I knew deep down it was AUTISM. I then told the doctor that I thought my child had autism and we were sent to the Klingberg Center for an evaluation. Sure enough, the diagnosis was autism.

I have had a lot of parents tell me that you never forget the day your child is diagnosed. How could you? That is the day your life really begins to change. I cried. I cried for weeks and felt this was not fair. I did everything I was supposed to. My child should not have autism. I felt I had lost my child. That is all I could think about.

I didn't want to believe that my daughter had autism. I thought if I did more research and Jenny started more therapy, Jenny would be ok. I WAS RIGHT, but not in the way I was thinking at that time.

One of my first steps was to call the Autism Training Center. Jenny soon became a registered client and we applied for the Family Focus Positive Behavior Support program. Soon there was a team of people all working to help my daughter. This is where everything really began to change.

The team completed a PATH, a person-centered planning tool. It was decided by the team that the most important thing was to work on Jenny's communication. The team decided to try the Picture Exchange Communication System (PECS). I did not want to do this. I thought that she wouldn't learn to talk if PECS was implemented. That was really what I wanted. I wanted my daughter to talk to me. But, this was a team effort and the whole team wanted to do PECS. We started PECS.

Jenny picked up PECS like it was nothing. I think it was harder for me than her. She got to Phase IV within weeks. This was her way to functionally communicate with us.

We attended more small team meetings and lectures and I truly began to understand autism. At one of the trainings I attended, the Educational Specialist made a comment that the Autism Training Center was looking for Community Partners. This is a parent who is a support to other families and helps them to find resources and many different things to help the family. I thought this might be something I would like to do, so I sent in a resume. I went for the interview and next thing you know, I was a Community Partner.

Jenny is currently doing well. She is in regular kindergarten and even has a best friend in the whole wide world. Just the other day she had a real conversation with me. I was right. She is doing great because she got the therapy and intervention she needed. She also gave me something no one else could. She has done so much in her little life. I realize now that Jenny was always my daughter. She didn't change because of autism. However, her autism did change me.

Transition to Independence: School-Based and Community-Based Education Program

By Barbary Shiley

Teacher, Huntington High School, Cabell County Schools

The goal of any transition program should enable the student to learn a variety of skills in school-based and community-based learning activities. The program must be structured so the student develops communication and social skills that allow the student to generalize and maintain skills appropriate to life situations. Appropriate high school transition programs must provide a balance of academic, vocational, independent living, communication, social/interpersonal, and leisure training.

Transition services must be written into each student's IEP. The Individuals with Disabilities Education Act (IDEA P.L. 10517) defines transition services as:

A coordinated set of activities for a student, designed within an outcome-oriented process, which promotes movement from school to post-school activities, including post-secondary education, vocational training, integrated employment (including supported employment), continuing and adult education, adult services, independent living, or community instruction.

The transition program at Huntington High School, located in Cabell County, West Virginia, has a major commitment to providing a program that promotes movement from school to post-school activities.

The program consists of: (1) functional academic programs to meet each student's particular needs; (2) school-based vocational and independent living skills training; and (3) community-based program which includes

grocery shopping weekly, mall trips, riding public bus transportation, eating out at least two times a month, bowling, and swimming weekly, as well as, picnicking at local parks during the Spring and Fall, and attending local festivals and special events.

One of the most critical turning points in the lives of students with autism is the transition from school to the world of work. The Cabell County School System provides, during high school, a work-based learning program for all students with disabilities. The work-based learning program provides all students with an opportunity to learn skills in a variety of businesses in the community. The training team consists of job developers who consult with business contacts to identify and analyze tasks to be done and develop ways these tasks can be taught most effectively, with the individual student's needs always in mind. Consultation is ongoing between the teacher, the job developer, and the job coaches. The job coaches consist of individuals with a variety of work experiences. Also, teachers of adolescents with autism serve as job coaches. Students are trained at different job sites to determine specific work interests. The concept of "readiness" does not apply. The student learns the job on-the-job. Our transition slogan is: "Learning to Work and Working to Learn."

High School education must be more than education in a regular setting. It must prepare your child and our student to live and work in the community as independently as possible.

Coming in the next
newsletter

- A Model Program for College Students With High Functioning Autism/Asperger's Syndrome.
 - What is Success for a Preschooler?
-
-

Video Views: Social Stories - the Video

By Amanda Glass

Educational Specialist Senior

The video, Social Stories, written and presented by Carol Gray, is a superbly presented communicative guide for parents, teachers and other professionals who work with children diagnosed with an Autism Spectrum Disorder. Carol suggests that social stories are quite often the key to improving a child's level of socially appropriate communication skills. These specifically written stories help children develop theory of mind (knowing what other people know) by using key words and illustrations. Social stories may be written to visually explain social events such as: waiting in line, greeting one another or playing on the playground. Carol has found this type of educational tool to be successful with many of her students. However, she is careful to say that this type of intervention does not work with all individuals. This video is recommended to anyone working with a person diagnosed with an ASD.



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Computer Corner

By **Kent Moreno**
Educational Specialist Senior

They say a picture says a thousand words. As individuals with Autism Spectrum Disorders (ASD) are primarily visual learners, the use of pictures can greatly enhance learning. Some possible uses for pictures in the development of instructional programming for individuals with autism include: as communication cards for the Picture Exchange Communication System (PECS), for use with a picture schedule, to add a visual component to social stories, or to make a reinforcement program more visual and thus, more concrete. In this issue of the Computer Corner I want to discuss digital cameras and scanners.

Currently, digital cameras are "hot." Most everyone I know either wants one or has one. As the owner of a digital camera, I have to admit they're kinda nifty. In truth though, they're not as handy as you might think and they're not going to be replacing cameras which use traditional film anytime soon. I say this for the simple reason that printing up your photos on a printer is an extremely slow process, is costly, and, depending on the inks in the printer, the pictures may fade after only a short while. There are businesses which will print digital pictures on traditional photo paper. The prices for this service are coming down but it's still more expensive than traditional photo processing. There is also the inconvenience of either having to burn the pictures you want on a CD-R or uploading the desired pictures to the business' web site. And should you connect to the internet via a standard phone line, depending on the size of the picture, expect from 5 - 10 minutes or longer to upload each picture.

At home, we use our digital camera to take pictures of our son's preferred items for his PECS book. In this respect, the use of photos is a nice addition to boardmaker because we can have pictures of specific preferred items rather than a general picture for toys or edibles. Because I'm using a digital image, I can re-size those pictures to meet my needs, edit them, or add text. Best of all, if a picture gets damaged, I can print up a new one in a matter of minutes.

With regard to buying a digital camera, expect to spend at least \$400 for a good quality camera. If you're considering buying a digital camera, one thing to keep in mind is that the technology is still fairly new and there is a lot of "garbage" on the market. Another consideration when buying a digital camera is the number of pixels (usually

referred to as megapixels). As a rule of thumb, if the pictures you want are 5 x 8 or less, a 2 megapixel camera will allow you to capture and print photo quality pictures. A 3 or 4 megapixel camera in this instance would be overkill and you'll be spending money for something you don't need. Currently, Olympus and Sony are making some very good digital cameras. For specific recommendations as to which camera to buy, I would strongly recommend the reader check the reviews in computer magazines or Consumer Reports before making a purchase.

A less expensive and possibly more useful alternative to a digital camera is a scanner. A scanner allows you to copy materials to computer files. In conjunction with a camera which uses film (traditional or Polaroid), a scanner will let you do everything you can do with a digital camera but at less than half the cost. An additional advantage to having a scanner is the ability to archive your child's records (evaluations, IEP's, IHP's etc) so, if the hard copies are ever lost or destroyed, a back up copy is easily accessible. With regard to scanners, both Epson and Umax make inexpensive scanners (under \$200) which routinely receive good or excellent reviews. Because models change so quickly I would again recommend reading the reviews for scanners in computer magazines or Consumer Reports prior to making a purchase.

The disadvantages of a scanner over a digital camera is more time and less convenience. With a digital camera, you take the picture, download it to a computer, edit the picture to meet your needs (if necessary) and print. Using a scanner in conjunction with a traditional camera, a desired picture is taken but you must wait for the entire roll to be used up before the pictures can be developed and then scanned. With a polaroid camera you bypass many of the time restrictions but the film is more expensive and the cameras are less flexible with regard to functionality (telephoto or close-up shots, red eye reduction, etc.).

Ultimately, what's right for you depends on your needs. If you're going to need a lot of pictures (more than 30) over a short period of time, then it may be worth the expense to buy a digital camera. If not, then the cost savings and the added functionality of a scanner is most likely your best bet.

Some sites worthy of investigation include:

www.shareware.com

www.tucows.com

[www.crayons.com/
links.html](http://www.crayons.com/links.html)

www.winsite.com

www.shareware.miningco.com

www.nickjr.com

www.trollbridge.com

www.download.com

[www.macshare.com/
sftwre.html](http://www.macshare.com/sftwre.html)



A LETTER OF INTENT: How It May Affect Your Child's Future.

news and views
Summer 2003

By Angela Bryson
Parent Support Coordinator

A "Letter of Intent" is a document that describes your wishes for your child, as well as specific information about your child that you would like others to know in the event you were unable to express your wishes yourself.

A Letter of Intent is not a formal legal document such as a Will but the courts will rely on it for guidance in understanding the current needs and wishes for your child. The court tends to favor the families' wishes as long as it is legal and morally right. A Letter of Intent serves many purposes. Not only can it describe your child's history and current situation; it also describes your hopes and desires for your child's future. This information can be used by direct care staff or future caregivers by providing knowledge and insight of the parents to provide the best possible care for the child in the event of their absence. If your child has a severe disability, caregivers would not have to waste precious time in learning appropriate behavior support techniques, medication administration or who provides services for your child.

Depending on your child's age and level of understanding you may wish to involve your child in writing the Letter of Intent. If your child is an adolescent or an adult you may receive valuable feedback from them on their future dreams and desires. If you have participated in the Positive Behavior Support process (PBS) most of the information for the Letter of Intent will be derived from the person-centered planning tools. If you have not participated in the PBS process, a good rule of thumb is to start with your child's current situation and list their needs, wants, resources and services.

It is a good idea for your Letter of Intent to be as detailed as possible. Your letter may be handwritten or typed. The choice is up to you. The length of the letter is also your decision. It can be 2 pages or 20 pages. This depends on how detailed you feel you need to be. Be sure to provide information on agencies that provide services for your child. You may want to include name, title, phone number and address of each contact person.

Some additional information you might include follows:

- Always include benefit programs, social security number and insurance numbers.

- You may wish to include a brief description of your family history, including names and addresses of supportive friends, neighbors and relatives.
- You should focus on the areas that will affect your child the most, such as, education, housing, behavior support, government benefits, insurance programs, social and religious activities, and future employment.
- You might want to include a summary of your wishes for future planning. Do not be afraid to express your dreams and desires for your child.

After you have written your Letter of Intent you may want to share copies with people closest to you and your child. Who you give copies of your letter to is up to you. Some families choose to share it with their pastor, close friends, other children, case manager or closest neighbor.

Preparing a Letter of Intent is an emotional experience. You will need time, patience and self-motivation to work past issues in addressing the future needs of your child. If you feel overwhelmed or are going through a crisis, now may not be a good time to start your letter. You might want to start the letter and draft small portions at a time. The letter is an on-going process to be taken out and reviewed periodically. It will need to be updated at least once a year. Always choose a date that has significance for you. My suggestion would be an anniversary, your birthday or your child's birthday. Review your letter, make changes, sign it and date it. Be sure the people you have given copies of the original letter to have the updated version. Also, if a significant change has occurred in your child's life, update the letter right away.

Finally, be sure your letter is easily identifiable and always kept in an accessible place. A good suggestion would be to keep your letter with a Life Plan if one has already been developed.

Suggestions for further reading:

- * National Institute on Life Planning for Person with Disabilities by Richard W. Yee
And Special Needs Financial Planning 2002
- * Planning for the Future/Estate Planning for Persons with Disabilities: A Division of Protective Life Insurance Companies
- * Frequently asked questions about special needs trust: www.nsn.com/frequently.htm
- * West Virginia Guardian and Conservator Handbook by the West Virginia Guardianship Commission

“Preparing a letter of intent is an emotional experience. You will need time, patience and self-motivation...”

SAVE THE DATE!

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