



AUTISM AND DEVELOPMENTAL DIFFERENCES TODAY

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A NEWSLETTER FOR PARENTS, EDUCATORS AND OTHER PROFESSIONALS

Are the best "Days" ahead? Looking forward to Adult Service Provision

By Lori Burrus

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Can YAP be the next "guiding light" in services for adults with developmental disabilities?

I love soap operas. They can be the canvas of our changing culture and more. Years ago we would not have seen someone with a disability on a soap opera. But in 2004, *All My Children* developed the role of "Lilly." She became a lead story for several years. She was an adult on the autism spectrum. She worked, married and dealt with her disability within the context of her community and family.

For me, soaps can have a sense of redemption, change and hope, not to mention all that drama!!!

In the last few years, YAP has seen a need to provide services to adult individuals with Developmental Disabilities. We have seen that need develop from children aging out of behavioral health, the staggering increase in the autism community, and a financially-strapped residential system no longer able to provide effective home and community-based services.

What does the world look like for someone under the age 21 with a developmental disability?

- Your auxiliary services paid through the education system (speech therapy, occupational therapy);
- You are picked up and dropped off at your doorstep by a school bus;
- You can have a school aide and therapeutic staff throughout your school day;
- You have an IEP through which a team can develop goals that must be implemented;
- You receive a menu of job experiences with a job coach;
- You have input in where you go to school;
- You have input in ensuring you are in a least restrictive environment; and
- You have the opportunity to attend school until you are 21.

And then we enter another world entirely—services after the age of 21:

- Auxiliary services are through a prescription and your medical insurance;
- Transportation is through a waiver budget or out of your pocket;
- There are waiting lists for services and jobs so you are no longer ensured a staff person;
- You may develop an ISP to determine your place on a waiting list;
- A budget is developed to determine which services you can receive for the year;
- You are given assessments to see if you can work, if at all; and
- Appropriate aging services are limited.

(Cont. **Days**, pg. 2)



Days (Cont.)

Enhanced Clinical Supervision

By Janet Crawford

The referring authorities are the Office of Developmental Programs and Bureau of Autism. The services being provided are goal/outcome-based and respite. They are set in the community and home.

So what do the services look like on a daily basis for adults? Consider John, who has had staff working with him for the past five years. John had many outbursts which at times required the police to intervene for the family's safety. The staff has built a relationship with John such that, in the last 4 years of their relationship, he has had no incidents and he is volunteering regularly in the community.

Let's now consider the couple with an intellectual disability who were involved in the Advocate program through Children and Youth because they were going to have a child. The Advocate program and the Developmental Disability program worked together with the couple and other team members to support them.

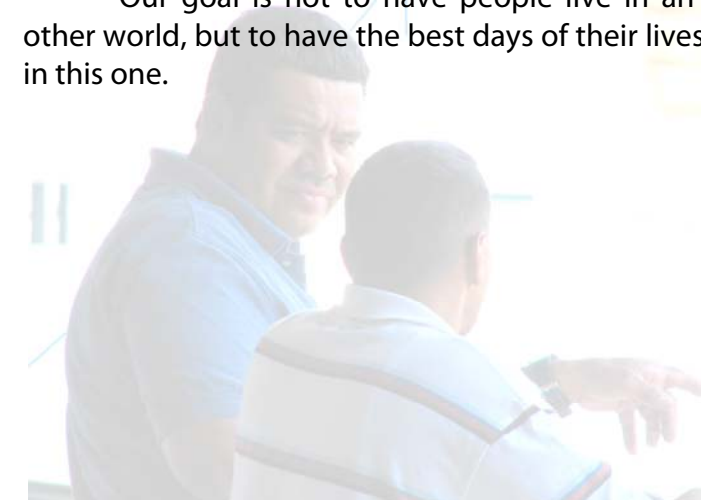
Then there is Joe, who lives independently. Following the death of his grandmother (his caretaker), there was concern that Joe would have to leave the only home he has ever known. It has been almost three years and Joe remains in that home, and is now attending Harrisburg Area Community College with staff support.

There are many stories within these programs. There is much collaboration between systems in these programs and there are many dreams and hopes being realized.

Our goal is not to have people live in another world, but to have the best days of their lives in this one.

What is "Enhanced Clinical Supervision" and why are you reading about it in the ASD Newsletter? This past spring, Ann Lyon completed the Autism Services Training with the Arizona Behavioral Health Program Therapeutic Support Staff (TSS). After completing the training, we were discussing options that would to keep the momentum of the training going for staff and to find the best way to implement these specific training strategies with the children and families that YAP behavioral health program serves. We wanted to ensure that we were utilizing the in house expertise to 'enhance' the local level clinical supervision for ongoing brainstorming and support. From those discussions, the "Enhanced Clinical Supervision" idea was developed. Twice a month, Ann Lyon, Kara Sherman, the AZBH Outpatient Therapist and Clinical Supervisor conduct a conference call with those TSS's that are serving children diagnosed on the Autism Spectrum. Not only have these bi-monthly calls served as an extremely valuable tool for children, families and staff involved, but it has also caught the attention of the provider network in which the AZ program operates. I attend meetings, at the request of referring provider networks to provide more information about the Enhanced Clinical Supervision as a component of our behavioral health services as well as information about YAP's Autism Institute.

This is an exciting time for YAP in Arizona around the Autism Initiative and the enhanced clinical supervision piece as many providers are looking for a choice when it comes to providing services to those diagnosed on the ASD.



A study: Christopher Cully

My name is Christopher Cully, I am 12 years old. I have been diagnosed with Aspergers when I was about 3 years old. I attend a regular school where I am in gifted classes. I do very well in school. I have always had Provider 50 services which included BSC's, MT's and TSS's. I have had several experiences that led me to believe that there were people who did not understand Aspergers and autism. This was very frustrating. Several years ago, my Mom took me to listen to a man named William Stillman speak about autism and Aspergers. I listened very closely. He spoke about treating people on the autistic spectrum with respect. I liked what I heard, then about a year ago, I met with Mr. Stillman and he helped me understand some of the difficulties I was having. The following day I went to another one of his seminars. I listened to him advocate for others on the spectrum. I met with Michele Miller and she asked me if I wanted to be an advocate. That was a very exciting opportunity for me and I agreed to make a power point presentation and help train new staff and advocate for people on the spectrum. I produced my autism advocacy presentation and I practiced it many times. I was asked to give my speech in June of 2009.

My parents and I traveled to Peckville, PA where there was a autism training session being held. I was a little nervous, but once I began speaking I became more comfortable.

The main idea that I wished to convey to others is that people on the autistic spectrum are quite smart and we don't get the respect we deserve. I do not feel as though my Aspergers is a disability, I feel it is an ability because I have learned more because of it and I want to keep learning. I have found that many times in my life people have treated me unfairly and disrespectfully. Some of the difficulties that I have encountered with lack of respect came from teachers, coaches, peers, BSC's, MT's, TSS's, and scout leaders and many neuro-typicals that simply do not understand the autistic spectrum individual. My goal in making my presentation was to educate and help others have a better understanding of what it is like to be on the "spectrum". I feel strongly that the new service providers have a clear understanding that the people they will be working with are intelligent human beings who may or may not be able to communicate in standard and socially acceptable ways. That they want to be heard and understood. They want to communicate with others. They want to learn. They want to be treated fairly.

Looking Beyond the Label

Western Pennsylvania's Crawford County YAP welcomed William Stillman to Meadville for a one-day workshop entitled "Demystifying Autism: An Inside-Out Perspective." The day was dedicated to changing our perceptions of those experiencing the Spectrum everyday with looking beyond labels and developing relationships. Marion Wells opened the event with a discussion about each person, who had a baggie filled with colorful candies in front of them. "What if there was a large label on the bag that prevented us to see all of the colorful candies that are inside? Now what if that label said Autism?" questioned Wells. The room fell silent. The point was to illustrate the importance of looking beyond the label and getting to know what is on the inside. Wells took it to another level when she continued to talk about the colorful candies that were both M&Ms and Skittles. "Both candies are very colorful, but taste very different once you get past the candy coating. Pointing out again that you shouldn't judge a book by its cover. That is part of the beauty of relationships, being able to look beyond the label with our friends and family living their life on the Spectrum."

Crawford County YAP staff all worked together to make this event a success. This began with greeting guests at the door, handing out name tags and folders with the day's agenda, sharing information about YAP and ACT 48 CEUs, selling Mr. Stillman's books, and selling raffle tickets and jewelry that the proceeds would go to Youth Advocate Programs Endowment Fund. Amy Fischer said, "It was a beautiful turnout of both professionals and family members who had many A-HA moments." Another YAP staff member Joyce Young commented, "...the seminar was helpful, I have heard Bill before, but I still learned some new stuff and refreshed some things I knew, and had forgotten. I have and will continue to use the things taught with my client."

Hopefully this Autism Awareness month brought the inside-out perspective to Crawford County. After all, who else better to learn about the Autism Spectrum Differences from than those who are living it!



Allegheny Truancy Staff sparks success

By Brian Kluchurosky

In early January, the YAP Truancy Program in Allegheny County was introduced to John, a 17-year old boy diagnosed with Autism, residing with his parents in a suburb of Pittsburgh known as McKees Rocks. John was very shy, and using a DynaVox to communicate, chose to remain out of the initial intake session. During that session his parents explained that John's current behaviors, most notably his refusal to leave the house, contributed to his truancy. In fact, it had been almost 9 months since John went outside, let alone attended school, some days not even leaving his bedroom. John would not say why he did not want to attend school and John's parents were left to speculate. Despite the difficult and complex circumstances, the YAP Truancy Program was initiated into action.

Early sessions revealed some progress with John as the aim for the Truancy Advocate Staff was to establish a rapport. John was receptive on some days, enjoying brief talks about the weather, but other days would turn the staff away altogether. However, eventually the genuine care of the Truancy Staff won John over and he became fond of their unique personalities, even growing a beard to match one worker in particular. It was at this point that talks about why John left school were attempted, but to no avail, as John would refuse to discuss the topic. During this time, John's parents, his mother in particular, took a vested interest in researching autism. Pouring over the writings of Bill Stillman as well as consulting with the YAP Autism Staff, a deeper understanding was uncovered, and previous potentially-damaging communication lines were replaced by positive, encouraging ones.

As the months went on, it became clear that the relationship between John and the Truancy Staff, as well as the relationship between John and his parents, was strengthening. Suddenly, John not only began going out of the house regularly, but he found a passion in walking outdoors, often leaving the Staff gasping for a break (no exaggeration). In June, John enrolled in a Special Needs Summer Camp where he interacted with other peers and adults, and engaged in a variety of activities, including swimming. Yet perhaps the greatest achievement to date is that John has decided to go back to school. In the fall he will attend Pressley Ridge to complete his Senior year and graduate. Not only is John meeting all the expectations of the YAP Truancy Program, but he makes you proud and fortunate to know there are people like him in this world.

Endowment Fund awards scholarship

By Robert S. Forrey

It has been a pleasure to work with David Pluta this past year. David has earned my respect on many levels. First, because of the relationship we have, is his disarming honesty. David has made mistakes in the past, he's willing to admit, but he does not live there. As a teen and younger man he habitually blamed others for his difficulties. Growing up with autism and being "different" from the other children caused some issues in his life. Mainly he had a chip on his shoulder from some of the things that happened to him. Having reconciled the past, David is free to talk openly about his experience.

Secondly, since I have known David, I've seen him work through various setbacks on the employment front as well as the educational front. While suffering disappointment, which is natural, David would come back and face the issue squarely, take responsibility for his actions in the matter and move on with a renewed vigor.

Thirdly, is his dedication to his Mother and extended family. While planning some lofty goals for personal independence, David remains loyal to the home front. While looking forward to his future of "new beginnings", David often shares his concerns about his Mother and how these changes will impact her. He keeps contact with extended family as often as possible and shares his personal victories.

David has enjoyed speaking at YAP trainings and is very appreciative of the award given to him. David is very aware of the realm of new possibilities that are opening up to him. Today, David makes every effort to approach life with a balanced viewpoint and a certain even-handedness. I'm sure David will do well as he is a Winner indeed!

John David Pluta was the recipient of a \$1,000 YAP Endowment Fund Scholarship, as presided over by David White, Endowment Fund President.



David Pluta receiving Endowment Fund check.

