#### DECEMBER 2009

# Arcticulate

The Arcticulate is a publication for employees and friends of The Arc of Northeastern Pennsylvania



Nick Hametz Story is on page 6

## TRANSITION - My opinion?

Submitted by Jeannie Lally, MAT, ABA Advocacy Service Director: The Arc of NEPA

TRANSITION - My opinion? It is never too soon to start thinking about it! The law requires that the IEP include a 'Transition Plan' when a student reaches the age of 14 but, by all means, start developing that plan sooner! After all, transition is a life-long experience. Often I advise persons seeking advocacy to "begin with the end in sight". This is not to say that parents should be able to predict the future, nor should they decide what the future will look like for their child. However, I do suggest that 'transition' be considered every step of the way. Do not just float in the boat; pick up the oars! When I speak about 'transition', in this context, I refer to the move, the shift... the evolution of 'Adult Life'. It may be easier said than done. It may be challenging, sometimes confusing, but, well worth every bit of effort. Transition is more a 'mind-set'. It is a way of living in today yet bearing an eye on tomorrow.



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I am going to offer some suggestions about the creation of the 'master plan' of transition and how to carve a path to get there! It is all about 'the plan' and the active pursuit of the related goals. Not surprisingly, children included in regular education are more likely to be involved with their transition plan. It is well established that active, meaningful, educational engagement is likely to lead to successful movement into the adult world. Similarly, students who have employment experiences during school are more likely to become employed.

Let's briefly review the school district's requirements, as set forth by federal law and corresponding regulations, in the IDEA: By age 14 the IEP must include measurable, post secondary goals for employment, education, independent living and must also identify appropriate transition services. These goals must be based on age-appropriate assessments, and include needs, strengths, and interests. The transition section of the IEP also includes a course of study and addresses the related services, community experiences, and employment that will be provided. The transition team includes the student, parents, professionals, teachers and anyone who might have important information about the student. The district further has an obligation to provide written notice, one year prior to the student reaching the age of majority and how that will affect the IEP

process.

Every school district must provide parents/guardians with their "Procedural Safeguards Notice." They do not, however, have any obligation to ensure the 'understanding' of the law, nor how these resources may be helpful! So, make sure you understand the law (particularly Section 504 of The Rehab Act, The ADA, FERBA, NCLB, and, especially, the IDEA), your rights, your entitlements, and how to get help. Understand service systems including: Local adult human services (including your county's Office of MH/MR) that are dedicated to your child's particular disability, health, estate planning, accommodations, representative payee service, transportation options, specialists, recreation/leisure, Office of Social Security, support groups, Office of Vocational Rehabilitation, counseling, job coaching/training... whatever your particular family situation requires. It is very important to know eligibility requirements, applications and appeals procedures. I suggest that you take full advantage of the IEP process to arrange visits to relevant services, schools, training centers, and an array of job opportunities in varying environments. Creating opportunities for the student to be exposed to adult community life is very important and may include various employment, living, and social environments.

(Continued on page 5)

## President's Message



It was the best of times, it was the worst of times, it was the age of wisdom, it was the age of foolishness, it was the epoch of belief, it was the epoch of incredulity, it was the season of Light, it was the season of Darkness, it was the spring of hope, it was the winter of despair, we had everything before us, we had nothing before us, we were all going direct to Heaven, we were all going direct the other way-in short, the period was so far like

the present period, that some of its noisiest authorities insisted on its being received, for good or for evil, in the

superlative degree of comparison only.

Thus begins A Tale of Two Cities, written by Charles Dickens nearly 150 years ago. As one reads and rereads that classic initial paragraph, one cannot but feel that it has applied to innumerable periods since and perhaps never more so in the past five decades than today. And yet despite all the current stress and tribulations, we all have so much reason to give thanks for our many blessings.

Specifically, The Arc of NEPA, as an organization that advocates and supports those with intellectual and developmental disabilities, has been blessed with dedicated and capable leadership for over fifty years. One need

only reflect on the contributions of Dr. Dominick and Claire Maldonato and Mary Campbell, the first executive director. Later Clay Richmond, Lou Dinner, Mike Barbetti, Bill Burnell and so many others contributed to the growth of our Arc. More recently Bill Burke and his parents before him, and his wife Carol have furthered the progress of this remarkable organization. The list, of course, is endless, and I know that I have neglected to mention numerous worthy individuals. The point, however, is the individuals we serve and the improvement in the quality of care and the growth of opportunities over the years.

The change in attitudes towards those with intellectual and developmental disabilities in my lifetime is extraordinary. This change applies nationally and statewide as well as in northeastern Pennsylvania. I speak from personal experience as a former school director for eight years prior to my involvement with The Arc of NEPA. The inclusion of students has been a positive for those included as well as those already "there" and the community at large.

As you consider your many blessings and as you offer prayers for those among us who are hurting, reflect on the gifts that those who preceded us have given and resolve to continue the work that they began.

Have a blessed holiday season,

Alan F. Hughes President

## Executive's Corner



In our last newsletter I commented that I wanted to discuss a renewed Arc PA priority of closing state institutions. I will get back to that in a minute, but first the PA state budget.

Fortunately, our message was received by the powers that be that services and programs to some of PA's most vulnerable citizens should not be cut. Waiver programs for the most part were left in-

tact. Base allocation funds were cut \$10 million statewide. The Office of Developmental Programs will attempt administrative cuts, but at most our department would lose up to 10% or between \$6,000 and \$10,000. We are committed to continue to provide the best quality, most affordable recreation programs to our consumers and family members. We will make this work, whatever it takes.

Discussion ensued over the past year that The Arc should renew its mission to close institutions in PA. To date, there are 5 public institutions in PA costing the tax-payer \$275,291,000 million serving 1230 residents. That is a whopping \$223,813 per person, per year; a staggering amount!

There are 2540 consumers in private ICF-MR facilities in PA costing another \$332,000,000 million at around \$130,343 per person, per year. Those numbers total \$607,291,000 million; well over one half billion dollars to serve 3770 people in public and private institutional settings.

On the other hand, we serve over 50,000 consumers in various community based services, spending approximately \$1.3 billion to do so. That is an average cost of \$32,000 per year, per person. Community Residential Services cost more of course, around \$83,115 on average. The problem is that we are running two parallel systems costing over \$1.9 billion, while over 22,000 consumers with intellectual and developmental disabilities are on the PA waiting list.

These numbers are staggering and hard to comprehend. The point is: should we continue to fund state centers housing people in large congregate settings at such an extraordinary cost, when we could serve so many more people in the community, get people off the waiting list, and spend limited dollars in tight budgets in a more cost effective and community inclusive manner.

I am not disparaging state center service workers or family members who believe in the institutional model, but we must come to the reality at hand. Institutions are extremely expensive, well past their time and an old fashioned idea that needs to be put to bed. The concepts of integration, inclusion, community living, and self-determination are where it's happening. 8 states have got it right, and have closed all their institutions. In PA, let us be next!

May you and yours have a wonderful, blessed holiday season.

Respectfully,

Donald W. Broderick Executive Director

## Residential/Adult Day Services

Submitted by Patrick T.Quinn

The change of seasons has certainly ushered in a very busy season in all of our licensed services. State licensing inspections are underway in both Community Residential and Adult Day services, and Lifesharing program monitorings are scheduled for later in the month. Good luck to all program personnel and thank you for your hard work throughout the year.

The Quality Forum group continues to meet regularly, and I'm happy to report that Larry Kochis and Lisa Jezworski have recently joined our ranks. Please remember that anyone can join the group discussion-quality is EVERYONE'S business. Feel free to telephone me or stop by the office if you'd like to become a part of the Quality Forum. The mission is simple: to provide the best quality services that we can, beyond regulatory expectations. The question we must ask ourselves is: "is what we provide each day for our consumers what we would want for our own loved ones, or even ourselves?"

Recently, Dick Tighe spearheaded the effort to provide a group training entitled "Words Can Heal". The training is aimed at recognizing the value of positive and purposeful communication between co-workers, and shedding light on the negative impact that gossip in the workplace can have. The philosophy is that positive communication between staff leads to a more quality service. Watch for upcoming announcements on

"Words Can Heal" trainings in the weeks to come.

Our United Way campaign for 2010 was an unbelievable success. We were forced to delay our in house campaign due to the state budget impasse and until our Administration and Personnel Committee of the Board of Directors could make recommendations for staff increases. With that behind us, we had only a little over two weeks to run our campaign. Given the state of the economy, we could not be sure how we would fare with employee pledges. Once again, Arc staff proved beyond a shadow of a doubt that we are one of the most generous contributors to the community United Way campaign in the region. Our goal was \$ 13,000. Our final tally was \$16,500, a new record for the Arc! Don Broderick informed me that he received a call from the United Way office informing him that the Arc's employee pledges put the Human Services division of the overall campaign over the top. To all of you, I thank you wholeheartedly for your generosity and giving spirit. It makes you very special, both individually and as a group, and I am honored to be your colleague.

Finally, thank you again to everyone in Residential and Adult Day Services for your continued commitment to those we serve and your hard work throughout 2009. I hope the holiday season affords you happiness, good health, and life's blessings.

## How to Get That Second Wind...

# Feeling run-down in this season of hustle and bustle?

You'll turn up the energy in five minutes if you... REFUEL. Snack on fiber-rich munchies such as dried apricots, celery sticks, an apples or a few pistachio nuts. Benefit: The fiber helps control the release of glucose (a sugar) into your bloodstream and may prevent energy dips.

#### BREATHE DEEPLY.

Every 1 – 2 hours, spend 5 minutes inhaling and exhaling deeply. It will help you feel calmer and more mentally focused, with renewed energy.

#### TAKE A VISUAL VACATION.

Close your eyes and mentally escape by imagining a peaceful scene on an island, in a meadow or by the ocean. "Seeing" yourself relaxed can be rejuvenating.

#### SNAP OUT OF IT.

Splash cold water on your face or p[op a breath mint - mint flavors are stimulating.

#### TAKE A "GOOD NEWS" INVENTORY.

At the end of the day, write down all the good things that happened. You'll be surprised at how much went right. Plus, you'll set yourself up for a good night's sleep...and energize yourself for tomorrow.

## Stopped in Traffic...

Submitted by Maryclaire Kretsch-Green

Stopped in traffic, I listen to "The Christmas Song" playing on the radio once again. I drift away for a moment as I recall the cover of the Firestone Christmas album, (volume 6, 7 or 8- we had many). The record spins on the turntable stereo in the old living room. One memory becomes many as I glimpse favorite images of holidays now dear. Traffic starts to move just as Nat wishes a "Merry Christmas to you". So I'm reminded, as I have been so often, of the many Christmases I've come to cherish. But this year I realize that the holidays have passed through stages over the years. I count four; the magical years, the young adult years, parenthood and the "I don't need any more decorations" stage.

When you're seven Christmas comes only once every five years. Thanksgiving to Christmas is forever. Hours watching the train circle the tiny town, putting your letter to Santa under the milk bottle on the back porch and jumping with excitement as mom read the telegram from the jolly ole elf himself; it is a season of wonder, over

flowing young senses with absolute delight.

Just as predictable as the tax forms arriving like clockwork each January, so too comes the Christmases of underwear and socks and frankly, just as boring. At thirteen, wishes turn from Barbie and GI Joe to music, sports, make-up and fashion. Fashion did not include black rubber boots with 18 buckles and hopefully Santa mom agreed. These are the cool Christmas years when you no longer get tucked into bed early on Christmas Eve but stay up past midnight and sleep in on Christmas morning. It's not so much family but friends at the mall. Cool gifts are the best you can hope for, (and maybe skipping the fruit cake preparation day at Grandma's). And so it is until the magic returns again.

Stage three- passing your memories along. As new mom, dad, aunt or uncle, it is imperative that you recreate

your childhood memories for the new little ones in your life. The magic of Santa, the tree, the train and stockings hung lives on in their wonder. We start anew as we build our own family version of the holiday. Enthusiastically and with careful thought we buy lights, ornaments and decorations that take us back and move our memories forward. The milk and cookies are left out for our nibble and once again we get little sleep not due to our over anxiousness but to complete the toy building, battery installations. "First Year Together", "Baby's First Christmas", matching stockings with names, they were all important in starting our own special meaning to the holiday. For a few years it seemed that there was always one more box of decorations to put away. We followed some of our parent's traditions and started some of our own. It was 25 years ago when I bought the box of red ornaments, once shiny now worn. I am watching time move.

It won't be long before my children start their own family traditions. I will tactfully (or not) push most of the decorations in my house to theirs. Stage Four- I refuse to buy anymore decorations unless it is small, convenient and replaces something else. This stage came on slowly. It started with me no longer feeling the need to display every decoration in the box. I became more selective. Once thought of as horrific, some actually ended up in the trash. It is time to step it down. My role in passing down Christmas memories and traditions is almost complete.

Stage four is reduction, simple, lovely reduction. I want one less box to put away this year as I find Christmas now in a quiet moment, in a carol, a passage, the innocence of a child, a family gathering. The years of memories and traditions are now within.

Wherever and how ever you feel Christmas, be it merry.

## Spotlight on Quality: The Unassuming Conductors

<mark>Submitted by Sheila Nealon</mark> Manager of Residential Services

As a provider, we are constantly striving to exceed regulatory expectations and ensure that all consumers associated with The Arc live full, self-determined lives. Simply put, we are committed to advocating for "everyday living."

We frequently recognize the staff who help individuals progress in fulfilling their dreams and living an everyday life; however, we often forget to acknowledge the "people behind the scenes" or the unassuming conductors.

These conductors need to be recognized for their devotion and dedication to staff and consumers. We would like to tell you something about one of them...

Every pay period, Patrick Quinn, Director of Residential Services, takes consumers out for lunch at his own expense. He does not broadcast that he does this—it's just taken for granted. He also volunteers his time and sings and plays his guitar at a local nursing home at least twice a year.

This past year, he organized and played at a benefit for two staff that lost everything in a fire. He does not expect gratitude or adulation- it's just a part of his unspoken, internal commitment to Quality. His actions are a blueprint for all staff and one of the reasons that we are so determined to insist on quality services.

Pat is part of an administrative team that advocates daily for the needs and wants of both consumers and staff. Too often, their efforts go unrecognized because they are working quietly in the background and shy away from acknowledgement.

As a team, all of us would like to shine the spotlight on them for a change and thank them for their unparalleled crusade for quality.

Don Broderick
Maryclaire Kretsch
Patrick Quinn
Jeanne Lally
Eileen Rempe
Marge Kearney
Sue Halley
Julie Verrastro
Tina O'Malley
Carol Franceski
Desiree Vojta

By modeling your determination to learn about resources, you will help to teach your child how to be **self-determined** and how to **self-advocate**. That is the first and most important part, of the 'master plan'. Keep all records and document all communications/contacts. Recognize the 'Big Picture".

Remember that you know and understand your child better than anyone. Know that you and your child are the most important members of 'the team'. Assume the role of a partner, an expert, and a collaborator. Exemplify respect. Celebrate what makes your child unique. Encourage, if not insist, that your child be an integral part of the transition team. Indeed, the transitioning student should aim to direct/chair the transition meeting. At first he/she may simply observe; it is all part of the greater 'process". Many sit on the bench before they get up and play the game! Ask open ended and reflective questions. Consider the development of a power-point or portfolio: photos, pictures, references, schedules, resume, best work, ideas, maps...map the plan, man! Practice interviews, role play, understand the disability...be self-aware and be selfregulating. Talk about it; it should not be the 'elephant in the room'.

All these very important skills can be taught through organized, direct and engaging instruction. It may take just a little longer; require a little more effort, a little more practice and a little more encouragement; but still, a small price to help an individual to become self directed and enjoy being an adult and an active member of their community. Help to draw out the student's preferences, priorities and dreams! "Independent" behavior is learned just the same as 'dependent' behavior. Be determined about self-determination!

Be prepared with the information that will pave the path. Invite others to participate in team meetings... consider a potential employer, friends that may later be roommates, post-secondary school reps, career centers, college students with similar disabilities; representatives from adult community agencies; whoever may have important information or play an important role in "the plan". Get these pieces in place well before graduation! Consider community based instruction...job shadowing, community colleges. Just ask. Be creative. Do not settle for what is available but reach for what is most rewarding and what will push your child's potential and raise that bar! There is little joy in marginality! Be realistic but shoot for the moon!

If strengths and needs are not so obvious, there are many assessment tools, both formal and informal. Interest surveys, questionnaires, aptitude tools, Functional Vocational Evaluation, ECT. Use them. Do not concentrate on weaknesses but, rather, focus on strengths. Which one of us would choose to pursue a goal where we did not demonstrate strength, skill, interest or talent? That is just silly. So, minimize weaknesses and build on strengths. That should be the heart of 'the plan'. Capturing fulfilling employment, education, training, social, and independent living situations are the 'bees-knees' and what we all want!

Focus on the acquisition of social skills, for they are the necessary tools we use in order to achieve and maintain the joy of human relationships and to be successful members of a community. Friends, family, schoolmates, teams, co-workers...ALL OF IT! Identify the social skills that need to be taught/learned and make it so! Socially important behaviors are absolutely essential to fully participate in adult life. Talking about the future should be everyday conversation. Consider options and "please pass the pepper"!

Remember the only one who does not make mistakes is the one who does nothing. Making choices is every**thing** we do. Make use of those choices. Talk about the outcomes of personal decisions, why did this happen? How could it have happened differently? Role play. This is how we monitor, evaluate and adjust ourselves. Are we even on the path, do we need to modify the path, are we doing what is best for us, do we need to make changes? Are we moving along on our "Master Plan"? The plan is alive and should change as individuals change or circumstances change. It is not stagnate. Revisit the transition plan frequently; modify and adjust. While a public education is your entitlement, use it to your full advantage; experiment with many opportunities. Make the most out of the transition plan! Be creative and remember to ask 'what if?"

Make it your business to know your entitlements, eligibilities, policies, providers, services and resources. Be involved in your communities and your government. And, if you do not understand any part of this, by all means, call an advocate! I happen to know how you can access extraordinary advocacy services! None of this needs to be really cumbersome or overwhelming. There is an abundance of useful resources and you are not alone! Support groups are great and there are also awesome informational sites on-line. Districts and IU's employ transition specialists and you should feel free to access their expertise. Go to the internet and look up model transition programs and plans. Pick out pieces that best suit your plan and plug them in! This comprehensive network should provide you with the information necessary to glide on into the adult world. And hence, the pursuit of adult life happiness!

## Foundation Overview

The poinsettia sale went really well. Thank you for your support. We continue to build the Foundation through very generous donations. As of right now, the End of the Year Foundation "Ask" was mailed and the returns are starting to come back to The Arc. We count on these donations to assist us in bridging the gaps in any of our agency needs. Also, we sincerely appreciate the kind thought when someone names The Arc as a beneficiary in a will or has made memorial or honorarium gift for a loved one. We are so honored to be remembered.

Please enjoy each other and the holiday season. May you be warm, well and happy. You are exceptional people who make the world a better place.

All of my best, Eileen



The Knights of Columbus Appreciation Party was held on November 16th. These fine gentlemen help The Arc to raise around \$15,000 a year. They have the Measure-Up campaign, coin canisters and Arc-Knight. Their dedication to our organization for the past 30 years is outstanding. We think they are a wonderful group and are very pleased with all the support continuing in Lackawanna and coming in from the expansion counties.

I am submitting the final report to The Arc-US for membership - due at the end of the year. Please do not forget about membership. If you are unsure as to whether you are a member, please do not hesitate to contact me and I will be happy to help you sign up. Your renewals are vital to our organization. As you know, the more members we have the more votes we have when it comes to legislative issues affecting the folks we serve.



## Arc Responds

A softball game was held against the Scranton Fire Department on October 14th. A little more than \$300.00 was netted and a donation was given to the Jim Robeson fund.

With the holidays approaching, we are expecting a number of requests for help.

## Nick Hametz Story

Nick has been with The Arc for 44 years. He resides in Weatherly in Carbon County with his mother Pat. He has a brother Tim, a sister Liz, and three nieces. Nick works at the Carbon Training Center (CTC); he has been working there since he was 22 years old.

Nick is one of the first students to attend the very 1st special education class in Weatherly. Besides working at the CTC, Nick volunteers at the Eckley Miners Village. He loves to work, but volunteering his time just shows how generous he truly is. The quality people most admire in Nick is that he is kind, helpful, and very considerate to others. He loves to smile and flirt, and has great social skills.

Nick is responsible for taking care of his bedroom and bathroom. His mother said that Nick's room is so

organized that it puts her room to shame. Nick's father passed away in 2008. He was one of Nick's best friends. They went out for breakfast on the weekends, as well as walked through the mall for exercise. His father played an important part in Nick's life. Frequent bouts of pneumonia keep Nick from enjoying the winter locally, so he spends three months in Florida every season.

## Public Relations & Development

Submitted by Eileen Rempe

#### **Auxiliary News**



The education committee has completed several readings this Fall. So far the outreach has been in the North Pocono and Scranton school districts, but is expanding to Mid-Valley and Catholic schools. The focus of the program is to promote awareness, acceptance and reduce the incidence of bullying. Several phone calls have been received for additional readings, but we have to schedule those for the spring. Also, the ladies would like to have Mikayla, the main character in the book, and her Mom come here for a reception at one of the local schools. Many good things are coming out of this program.



There was a recognition luncheon for Carol Burke on November 4th. She is an inspiration to all of us and we are so thankful for her dedication, vision and commitment. What a surprise when she saw how many of her family and friends wanted to join in her celebration!



The ladies worked very hard on putting together a Christmas tree exhibit for the Trolley Museum show held on December 3rd. Their tree won "People's Choice!" The theme this year was "The Joy of Giving." The ladies made their tree's message - the Joy of Giving on a Budget. The tree was adorned with little ideas for making a better holiday, such as "Visit with a lonely neighbor." We have a few artists whose talent is amazing. Speaking of which, Maron Bielovitz, the Auxiliary Secretary, had her first Art show opening on November 6th. What beautiful work she does. Also, Maron recently put together the Auxiliary's first newsletter. Extraordinary gifts all in one beautiful bunch!!

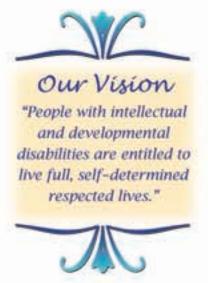
Each woman serving on the Auxiliary is beyond exceptional to work with and I admire each and every one of them for their strength and elegance.



The Arc Parent Group held their holiday party at The Parish Center on Sunday, December 6th. Coopers provided the wonderful food, Santa, Mrs. Claus and the elves were a hit, the baskets were beautiful and the dancing and music (by DJ John Serkosky) was really great! Fun was had by all and the event was spectacular. Hope you can join us next year.



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### Membership is the key...

You can help, Become a member of The Arc of Northeastern Pennsylvania today, Benefits include:

- National, state and local newsletters with current information on intellectual and developmental disabilities
- . The opportunity to participate in The Arc affairs at a local, state and national level.
- Attend conferences, conventions and seminars at a reduced cost.
- Discount prices on publications.
- Insurances services, credit card programs and long distance telephone services.

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