

# THE ADVOCATE

News of Delaware County Advocacy & Resource Organization, PA Summer, 2018



Delaware County  
Advocacy & Resource  
Organization

Thank You to everyone for making our 2nd Annual Golf Classic a **HUGE** success!!!



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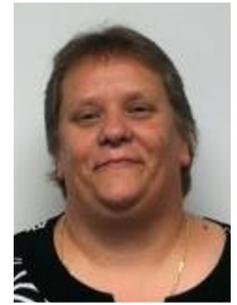
**Geralyn Arnngo**

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The summer is finally here after the winter that would never end!! We were grateful that on May 7, we held our Annual Golf Outing on a beautiful sunny day, which was a huge success. Many thanks go to our Past President, Colleen Shepherd and the whole Golf committee along with a host of volunteers! Our golfers enjoyed the day and raised money through not only golfing but buying 50/50, raffles, and the most exciting event which was a helicopter ball drop to win a cash bonus! As we prepare now for our upcoming budget, we reflect on all that we do to serve our membership. We continue to seek new grants, new initiatives, and new donors to keep Delaware County Advocacy and Resource Organization (DCARO) strong! What keeps us empowered to do the work we do? It is the members we serve, their smiles when they come to events, the Thank You's we get when we advocate for a family, and the relationships we continue to build in the community. You might want to ask yourself the same question..... What empowers you to support DCARO? I can personally answer that because I am a parent of a young man who has taught me so much over the years. He empowers me to be of service! Let us know how you can help. We are always looking for ways for the membership to get involved and our board has several committees that we can use your help. Come learn what the fundraising, outreach or even the legislative committee is doing by attending one of our meetings. Email me at [president@delcoadvocacy.org](mailto:president@delcoadvocacy.org) or call the office at 610-544-6600.

*Diane*



Happy summer and boy has it ever arrived! As I sit writing you this message and contemplating our theme of Empowerment for this issue, I am overwhelmed by just how many things come to mind but by none more than the actual definition of the word.

Em – pow – er – ment: 1) authority or power given to someone to do something; 2) the process of becoming stronger and more confident, especially in controlling one’s life and claiming one’s life. It occurs to me that perhaps #3 in this definition should be Delaware County Advocacy & Resource Organization. Why you might ask? Because that is our mission, our vision, our path and our goal! Across all of our programs, our Education and Adult Advocacy, our Social/Recreation Program and our membership our focus is constant; to provide our community living with intellectual and developmental disabilities and their families the “power” to “claim and control” their own lives. By providing assistance, support, membership and knowledge Delaware County Advocacy & Resource Organization consistently pursues the belief and practice of individuals envisioning, planning for and executing their own Everyday Life. By empowering families to pursue the education each student is entitled to, by empowering individuals and families with knowledge to navigate the adult service system and pursue competitive employment, and by empowering individuals to develop social skills and participate in community inclusive events, Delaware County Advocacy & Resource Organization identifies each day as the true 3<sup>rd</sup> piece of the real definition of Em – pow – er – ment!

Everyone here at Delaware County Advocacy & Resource Organization are proud of our role in our community and will remain dedicated to our mission, our vision, our path and our goal to EMPOWER!

*Eileen*

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## Empowerment

“Authority or power given to someone to do something. The process of becoming strong and more confident, especially in controlling one’s life and claiming one’s rights.” This is the definition the dictionary provides to describe Empowerment.

As an advocate and a closet control freak it is easy for me to do work for others. To take on their projects, fill out a form on their behalf, do something *for* them. Would it make my job easier? Yes. Will it teach my clients to help themselves in the future? No. I’ve learned in this job that when I partner with my clients and their families to cultivate a relationship of growth, learning, and progress that this becomes a more sustainable model for them to use in the future. As a well-known quote says about this principle, “Give a man a fish, and you feed him for a day. Teach a man to fish, and you feed him for a lifetime.” Our program works to give our individuals the skills they need to tackle obstacles they encounter within the various systems they depend on for supports. When they feel empowered about the services, roles of team members, and what they are asking for then they are able to confidently advocate for themselves. Knowledge is power and when our clients understand the complexities of their services they become the authority.

“Power can be taken, but not given. The process of the taking is empowerment in itself,” by Gloria Steinem. I think this quote is very applicable to the individuals we serve. I often find that the “system” will be quick to make choices for my clients. Families are afraid to speak up and fight for what is right. The power is often in the hands of the “professionals.” I include myself into this category because I am often reminded by my clients and families that they are in the end, the decision makers and will choose the best path for them. My role is to not only advocate for what my clients need but show them *how* to ask for it. In providing them with the right jargon I am forcing them to take back the power that is rightfully theirs. Through a person-centered focus my goal is to always keep the individuals I serve in the middle of the decisions

and a part of the process.

“One of the most stubborn barriers to patient empowerment is the cultural assumption that since the way professionals learned was hard, you must need to be really smart, and you need to be taught in a carefully thought out, methodical sequence,” by Dave deBronkart. We have to break the thinking just because someone has letters after their name that they are somehow more intelligent than the person living through “it.” In my role, I have learned the most from parents because they have spent their entire lives researching, learning, and educating themselves on how to better serve their children.

With love,

*Karissa Desiderio, MSW*



Karissa Desiderio, Adult Advocate  
Can be reached at ext. 110  
kdesiderio@delcoadvocacy.org

## Extra Hands on Deck

There are some extra hands on deck working with the Education Advocacy Program. Here's a brief introduction to both Ethan Yoo and Joanna McGowan.



My name is Ethan Yoo (he/him/his) -- I am so excited to work this summer with Nicole Mendez, friends and members of the Organization, and fellow staff as the Education Advocacy Project Assistant! As the Education Advocacy Project Assistant, I will be attending 504, IEP, and mediation sessions with Nicole; assisting with the navigation of our grant to intervene in the school to prison pipeline; and getting to know you! As for myself: I am a rising senior at Swarthmore College, majoring in Educational Studies and Political Science. In the coming months, I intend to apply to graduate school programs in social work, as well as for employment opportunities in the mental health field; ultimately, I hope to become a licensed clinical social worker.

My interest in disability rights is both academic and personal. I have a health impairment that sometimes inhibits my access to resources, and I receive accommodations at the college level that intersect physical disability and psychological health. As a result of these experiences and my identity as a first-generation college student, increasing access to education (on the basis of financial, identity, informational, and/or dis/ability status) is of great importance to me. I have taken academic courses discussing dis/ability and trauma including: Urban Education; Im/Perfect Bodies and Dis/Ability Studies; Culture, Health, and Illness; and Adolescence. I also served on Swarthmore College's Search Committee for our new "Director of Student Disability Services" this past spring.

My amateur interests include computer hardware releases and software updates, music performance, film, and writing.



Empowerment. It's a buzzword we hear a lot lately. When it comes to our areas of expertise, we can feel really good about this word. But when we are in unfamiliar territory it can feel overwhelming. This is especially true for special needs parents. We want to be empowered to make the best decisions for our children, but there are SO MANY things we need to worry about. Education, services, medical needs, diet, therapies – the list is endless. To a special needs parent who might have to plan for two weeks just for a grocery store outing, becoming empowered can just seem exhausting.

But no one knows more about or cares more for your child than you. When it comes to your child, leaving everything up to the experts is simply not an option. But just because empowerment is important doesn't mean you have to do it alone.

Below are some suggestions to become empowered to help your child – and yourself! And of course, the Delaware County Advocacy and Resource Organization is here to help. Be sure to check out their web site, services, and upcoming events!

### Join a Parenting Group

There are tons of parenting groups out there – there has bound to be one centered specifically around your specific need. A local group is great, but if that's not possible or available, social media has made finding your tribe easier than ever. In addition to finding support, this is a great source for local resources. It can also save you a ton of time researching. If you ask your group a specific question, chances are there is a veteran parent who can point you in the right direction or even has the research on hand.

### Take Advantage of Free Trainings

There are lots of free resources for parents out there – check with your local advocacy group, your local library, community center, or the parent groups mentioned above. You can find in-person and online information about special education law, parent rights, therapies, and more. Download podcasts to listen to while cleaning or driving!

### Communicate

Communication is the key to every success, and this is very important when it comes to your child. Be open with teachers and other professionals about your goals for your child, your concerns, what has been working at home, etc. Open communication helps everyone work toward a common goal and helps to alleviate concerns on both ends. So make sure you are checking in with everyone on your child’s team and maybe have a communication log to ensure that you and professionals are on the same page.

### Document Everything

This goes along with communication, and is it very important not just for disputes but also for everyday needs. You should always keep a record of your child’s goals and activities, as well as diet and medication, and behavior, sleep schedule, etc. Special needs parents are juggling a lot and we don’t always remember everything that was going on at any given time. If your child has a sudden regression or behavior issue, documentation will help you to pinpoint the cause. If something happens that also happened years ago, you will be able to look back and see common factors. And if you ever need to prove that something was successful or unsuccessful, or explain something to your team, you will have the documentation you need to support your request.

Remember – you don’t have to go it alone. There is help to empower you to feel good about the decisions you make for your special needs child!

Joanna McGowan has a BS in Psychology, an MA in Student Services, and certifications in School Counseling (K-12) and Yoga (RYT 200). She is trained in vinyasa flow with an emphasis on trauma sensitivity. She is passionate about healthy living, which she writes about at [HolisticallyWhole.com](http://HolisticallyWhole.com).

Joanna has been practicing yoga for over a decade, but her son who has severe autism inspired her to bring the fundamentals of yoga to populations not typically exposed to the yoga studio. She is currently teaching yoga at drug and alcohol treatment centers, and therapy centers for children with autism.

Joanna is bringing her expertise to our Engaging Support Enriching Lives; A Combatting The School to Prison Pipeline Project to help institute mindfulness and yoga practices in Delaware County Schools.



*Nicole Mendez, Education Advocate  
can be reached at Ext. #107*



Delaware County  
Advocacy & Resource  
Organization

740 S. Chester Road, Ste G  
Swarthmore, PA 19081  
610-544-6600 (P) / 610-544-8916 (F)

# AGAIN???. YES.... AGAIN

## Back by popular demand...it's the Brewhaha Bingo Bash!!!

**Who:** Guys & Gals (Prizes are Guy and Gal friendly)  
All guests must be 21 (ID required)

**Date:** Friday, September 14, 2018

**Time:** 7 pm Bingo begins promptly at 7:30 pm

**Where:** Ridley's Creekside Center  
794 Milmont Avenue, Swarthmore, Pennsylvania 19081

**Cost:** \$35 per ticket, limited Tickets available. Ticket price includes 6 BINGO games with cash prizes for each game, as well as Roast Beef sandwiches, salads, beer, wine and soda.



**CASH Prizes**

**FOOD**



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100% of all funds raised will be donated to Delaware County Advocacy & Resource Organization (formerly The Arc of Delaware County).

*This is sure to be a evening of fun and laughter. Raffle tickets for various baskets will also be sold.*

Tickets for this event can be purchased online at [www.delcoadvocacy.org](http://www.delcoadvocacy.org) or by sending a check or money order made payable to Delaware County Advocacy & Resource Organization to 740 S. Chester Road, Suite G, Swarthmore, PA 19081.

**F  
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N**

## Empowerment Through Communication

Recently the American Speech- Language-Hearing Association (ASHA) put forth the following statement:

“It is the position of ASHA that the use of RPM is not recommended. Furthermore, information obtained through the use of RPM should not be considered as the voice of the person with a disability.” The full ASHA statement can be found here: <https://www.asha.org/uploadedFiles/Rapid-Prompting-Method-Peer-Review.pdf>

Below is the response letter written by a group of non-speaking autistics who use a letterboard to communicate.

American Speech-Language-Hearing Association  
Attn: Board of Directors  
2200 Research Boulevard  
Rockville, MD 20850-3289

June 23, 2018

Dear ASHA Board of Directors,

We are a group of young adult non-speaking autistics from the Philadelphia area, known as “The Gang.” We use a letterboard to communicate. Please accept our comments below regarding your drafted Position Statement concerning RPM:

G: My name is Gregory and my life was forever changed by a letterboard.

A: My name is Alex and a year ago I was freed from silence when I picked up a letterboard.

N: My name is Nasser and I use a letterboard to communicate.

K: I am Kevin and I have autism and spelling to communicate has made me finally have a voice.

S: My name is Sarah I have autism and I am communicating with you today via letterboard.

B: I am Brian and I am an autistic adult who communicates by spelling my thoughts.

G: For years I went to countless therapies and doctors who all believed the issue was my brain. Well guess what? They were wrong. No one ever assumed the problem was with other people’s presumptions about my abilities.

A: I have tried every therapy and doctor imaginable. Until this year I sat in a classroom learning about preschool level content. For the first time in my life I am feeding my brain with content to make it grow, all because of Letterboard.

N: Want to know what therapies I’ve tried? You name it, I’ve tried it. Until spelling to communicate, everyone said my brain was the problem. Why is that? Because I assure you that is not the case.

K: I’m going to be blunt about this. No therapy has worked as well as Spelling to Communicate. That includes evidence-based therapies. Those supposed therapies treated me like I was an idiot. Spelling to Communicate has never once presumed I am incapable.

S: I have been through every practice you can imagine. None have yielded the results of Spelling to Communicate. This therapy is life changing. It has given me the opportunity to participate in life rather than be a bystander.

B: Think of every therapy. I have been through it. None have come close to Spelling to Communicate. I implore you to observe a session. You cannot unsee this.

G: For the first time in my life I have been able to make decisions for myself. Earlier this year I was able to use the letterboard to express myself during a medical scare. To say this is life changing is an understatement, it is lifesaving.

A: For the first time in my life I have a say. From what I want to eat, to how I dress, to my medications, I finally have a sense of control.

N: People take for granted their ability to make decisions. I finally have the ability to contribute my opinion on decisions about my life. That was also made possible by Spelling to Communicate.

K: Prior to spelling I lived a life of 24-7 stress. Think of the most stressed you have ever been. That was my daily life. Spelling helped open the door to express my struggles.

S: Prior to letterboard nobody thought I could be capable of intellectual thoughts. Now people talk to me like I am a functioning adult. My family dynamic has changed for the better. I am closer to them than ever.

B: Since starting Spelling to Communicate I have a new perspective on life. I can talk to my loved ones. I can tell my brother to stop being an idiot. My language is now more expressive. I can now make more decisions regarding my life. I can also flex my pristine wit and sense of humor.

G: You would rob me of the ability to play an active role in my own life, if you do not open your minds to this method of communication. I am not only speaking for myself, but non-speakers everywhere.

A: The consequences regarding this decision are huge. I am talking restricting education to just neurotypicals. That is not what makes our nation great. We are a country that was founded on ideals that ideas are to be discussed not rejected just because they are different. This decision contradicts that ideal.

N: This would rob me of a full education. I have a hunger to learn. Keeping me in special ed classes will only hinder my potential. That shouldn't be the goal of the education system.

K: This decision does not directly affect me but it does have an effect on my friends. That I cannot idly sit by and watch. I ask you to reconsider your stance.

S: I need this method. It has allowed me to build friendships and communicate with my loved ones, don't take this away from me.

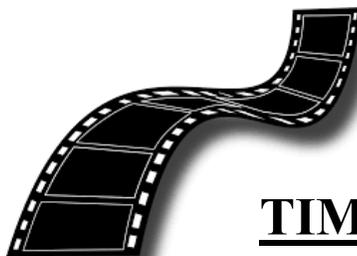
B: I have spent the majority of my life in silence and I don't want that to be the case for anyone else moving forward. There are communities across the country similar to ours here in Philadelphia who want to make this change to prevent future non-speakers from spending their life in silence.

Sincerely,

The Gang  
 Gregory Tino  
 Alex LePape  
 Nasser Zolali  
 Kevin McGinnis  
 Sarah Ackerman  
 Brian Foti



**WHERE:** DCIU  
200 YALE AVEUE  
MORTON, PA  
RM 171-172



**TIME:** 6:30-8:30 PM



**COST:** \$5 INCLUDES  
POPCORN & A DRINK



**JULY 18, 2018**



**AUGUST 20, 2018**

## SAVE THE DATE!!!!

Our Holiday Dance,  
(*OTHERWISE KNOWN AS OUR  
BIGGEST PARTY OF THE YEAR*)  
will be held this year  
on December 9th, 2018.

More details to follow soon.



**KEEP AN EYE OUT FOR  
INFORMATION ON OUR  
UPCOMING FALL SOCIAL/REC  
EVENTS!!!!**



## Help Wanted IM4Q Team Monitors

Delaware County Advocacy & Resource Organization is seeking individuals who are interested in becoming IM4Q (Independent Monitoring for Quality) Monitors to perform interview surveys. Training will be provided for the position. The position is part-time and extremely flexible. It's perfect for retired individuals or anyone who wants to supplement their income. A stipend for each survey completed and returned will be paid.



If you are interested in this position, please contact Vera D'Ercole at 610-566-4400 ext. 109.



Delaware County  
Advocacy & Resource  
Organization

Free Wash!

BRING  
ALL  
OF  
YOUR  
CARS

TELL  
YOUR  
FRIENDS  
AND  
NEIGHBORS

740 South Chester Road  
Swarthmore, PA 19081  
Community Interactions  
Parking Lot  
Saturday September 8th  
10AM—2PM

*Delaware County Advocacy & Resource Organization  
Representatives will be available to answer questions*



Donations will be accepted

All proceeds will benefit Delaware County Advocacy & Resource Organization's  
commitment for advocacy among our community of individuals living with  
intellectual and developmental disabilities

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**Advocating for inclusive community practices and influence public policy for individuals with intellectual and developmental disabilities**



**Delaware County  
Advocacy & Resource  
Organization**

*Delaware County Advocacy & Resource Organization (Formerly known as The Arc of Delaware County)*

*Delaware County Advocacy & Resource Organization is a 501(c)3 non-profit organization - donations to which are tax deductible to the fullest extent permitted by law. The official registration and financial information of Delaware County Advocacy & Resource Organization may be obtained from the Pennsylvania Department of State by calling toll free within Pennsylvania 1.800.732.0999. Registration does not imply endorsement.*

United Way of Southeastern Pa · #00348